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FOREWORD

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Bruce Hill

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Date

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Introduction

Compared to white women, there is a dearth of information about the screening practices, beliefs, and psychosocial interventions targeting African-American women, especially those with a family history of breast cancer. Although white women have higher incidence rates of breast cancer than African-American women, especially above the age of 50, African-American women have higher mortality rates resulting from the disease (1). For example, after controlling for stage of disease, geographic location, comorbid conditions, and sociodemographic characteristics (e.g., age, marital, status), African-American women are almost twice as likely to die from breast cancer than white women (2).

Detection of breast cancer through mammography screening offers hope for decreasing mortality rates from breast cancer among this population. However, trends in screening show that African-Americans adhere poorly to recommended screening practices. For example, data from the 1992 National Health Interview have found that while 64% of African-American women have ever had a mammogram, only 32% have had regular screening mammograms (3). Of import, these population statistics do not address the screening practices of specific high risk groups such as African-American women with a family history of breast cancer. Indeed, there is a lack of information explicitly exploring the mammography screening history of African-American women with a family history of breast cancer. What little is known suggests that these women are less likely to adhere to recommended mammogram screening intervals compared to white women (4), and that they rely more strongly on clinical and self-breast exams than mammography as detection methods despite their decreased effectiveness (4). Unfortunately, the ability to generalize these results has been limited due to the small sample sizes ($N \leq 60$). Thus, one of the objectives of this proposal was to report on the mammography screening history of African-American women with and without a family history of breast cancer.

A second goal of the proposal was to assess and compare risk perceptions among African-American women with and without a family history of breast cancer, and also to examine how these risk perceptions affect intentions to get a mammogram. Poor adherence to mammography screening may in part be the result of a lack of knowledge about the risk factors for breast cancer and/or low levels of perceived risk of getting breast cancer. Indeed several models of health behavior such as the Health Belief Model, Protection Motivation Theory, and the Precaution Adoption Model suggest that heightened perceptions of risk should facilitate behavior change including mammography screening (5-8). A recent meta-analysis of the extant literature supports a positive relationship between perceived risk and mammography screening (9).

The extant literature suggests that African-American women are less likely than white women to recognize family history as a risk factor for breast cancer, even among African-American women with a family history (10). This lack of knowledge is consistent with the lower level of knowledge that African-Americans, especially the poor, have of cancer risk (11-14). These results suggest that preliminary interventions should at least provide educational materials that alert African-American women of the risk factors for breast cancer, which may be quite effective among African-American women with a family history (15), while highlighting the effectiveness of mammograms. The present study examined these issues and assessed the effectiveness of the intervention using the Transtheoretical Model of behavioral change. A brief overview of the Transtheoretical model follows.

The Transtheoretical Model

The Transtheoretical Model (16) suggests that behavioral change occurs in a sequence of stages. The primary stages are precontemplation, contemplation, action, and maintenance. Precontemplators are not considering changing their behavior; contemplators are considering changing their behavior; people in action have initiated behavior change; those in maintenance have maintained the behavioral change over a specified duration. Therefore, people in different stages of change exhibit different patterns of beliefs, feelings, and behaviors across stages but show similar patterns of beliefs, feelings, and behaviors within a stage.

Movement across stages is mediated partly by a person's views of the pros and cons of changing the behavior (17). The pros represent the potential benefits of change, while the cons represent the disadvantages of change. The overall weighing of the pros and cons is called decisional balance. Studies reveal that the weighing of the pros and cons differ across stages. In a review of 12 different health behaviors, the cons outweigh the pros for people in the precontemplation stage; an increase in the pros marks a change from precontemplation to contemplation, and a change from contemplation to action involves a decrease in cons (18). The important implications of these findings are that: 1) interventions aimed at moving people from precontemplation to contemplation should stress the pros of changing the behavior, and 2) movement from contemplation to action should emphasize decreasing the cons for change. Thus, an aim of this study was not only to describe mammography screening patterns via stages of change, but also to assess whether modifying the pros and cons of change via the use of message framing affects movement across different stages as described above.

Message Framing

Efforts to motivate people to follow recommended health practices have at times presented factually equivalent information as gains or losses (19-21). Gain messages stress the potential benefits or advantages of following a recommended action; loss messages emphasize the risks or disadvantages of not following a recommended action. The framing of messages as gain or loss has a differential impact based on a psychological reference point. Based on prospect theory (22), people tend to be risk averse when it comes to gains but are risk seeking when it comes to losses. That is, people prefer not to gamble when they have a sure win (i.e., gain), but prefer to take a risk to prevent the possibility of a loss. Hence, loss-framed rather than gain-framed messages should be more effective for persuading people to adopt a change in health behaviors that are perceived as risky (22). From this perspective, mammography screening can be considered a risky behavior since there is the possibility of finding cancer; therefore loss messages should affect breast cancer screening behaviors more so than gain messages. Indeed, this is what the extant literature shows (19, 23). Moreover, loss messages should be particularly effective in persuading women who are at high risk (e.g., African-American women with a family history) or perceive themselves at high risk, since psychologically they perceive themselves as having more to lose from not getting a screening mammogram. With respect to stages of change, gain messages should be more influential in moving women from precontemplation to contemplation, while loss messages should be more powerful in moving women from contemplation to action. The present study tested these predictions with respect to message framing and perceived risk as well as message-framing and stages of change.

Method

Participants:

Women with a family history were recruited by first contacting a first-degree relative (N=91) diagnosed with breast cancer based on the information provided by Duke University Medical Center's Tumor Registry. Eighty one of the 91 women consented to give the names and phone number of their first degree relative(s). Data on stage, length since and mean age at diagnosis were available on 69 out of the 81 breast cancer patients who consented to give the names of their relative(s) – this information can be obtained from the PI upon request. Referring patients at times provided the names and phones numbers of more than one first-degree relative.

The sample of African-American women without a family history of breast cancer (i.e., controls) was obtained from a sampling frame of all African-American women who attended the Duke Radiology Department within the last 3 1/2 years. To obtain comparability between groups, controls were matched with women with a family history based first on age (within \pm 6 months), and then on mammography history (\pm 3 months of most recent mammogram). Since this study was aimed primarily at affecting mammography screening, age and most recent mammogram were viewed as the two most critical matching variables based on the limited sample size of African-American women. Including other matching variables, such as education, would have resulted in fewer successful complete matches.

Attempts were made by phone to recruit 384 women (233 controls and 151 with a family history). Of these 384 attempts, 194 controls and 151 women with a family history were reached. Among those reached, 45 controls and 15 women with a family history refused to participate, and one control and two women with a family history initially consented to participate and later revoked consent at the time of the baseline interview. In addition, 12 controls and four women with a family history could not participate for other reasons (e.g., health reasons, wrong race). The final sample consisted of 130 (86% response rate) and 136 (70% response rate) African-American women with and without a family history of breast cancer, respectively. The demographic characteristics of study participants are presented in Table 1. The groups did not differ significantly on any of the demographic characteristics. Overall, 111 successful matches were made on age, including 75 matches on both age and screening history. Only 15 women with a family history of breast cancer could not be matched with a control.

Overall, there were 136, 133, and 129 women without a family history at baseline, the three-month follow-up, and at final follow-up, respectively. There were 130, 128, and 126 women with a family history at baseline, the three-month follow-up, and at final follow-up, respectively. The demographic characteristics associated with study participants are presented in Table 1 across all three waves of the study. Overall, the demographic characteristics remained stable across all time points. There were no differences among these women with respect to age, education, marital, or work status.

Procedure: Study participants were mailed a cover letter to their place of residence describing the study. They were contacted by a trained telephone interviewer from the Duke Risk Communications Laboratory (RCL) within two weeks of the mail out. Participants reached were reminded of the purpose of the study, and those who agreed to participate took part in a 15 minute baseline interview – data were collected using a computerized telephone interviewing system (CATI). The interview consisted of obtaining information about the participant's: 1) mammography screening history, 2) intentions to have a mammogram within a specified time

interval (e.g., next 3 months for women who were off-schedule, or within a year or one to two years for women who were on schedule and either at or above age 50 or below age 50, respectively), 3) pros and cons of mammography screening (i.e. decisional balance, 24), 4) knowledge of risk factors for breast cancer, 5) perceived risk of and worries about getting breast cancer, 6) attributions for their perceived risk of breast cancer, 7) interest in genetic testing for breast cancer risk, 8) psychological well-being, and 9) demographics. A copy of the baseline questionnaire is provided in Appendix A. Baseline interviews were first conducted with women with a family history, and then controls were called after being matched by age and secondarily with screening history. Participants were paid \$10.00 for their baseline interview.

After responding to all questions, participants were reminded that they would get a brochure in the mail within three months that discusses breast cancer and mammography screening. They were asked to read the brochure, and informed that a second telephone interview would occur about two weeks after getting the brochure, in order to obtain their impressions of the material.

Approximately three months after the baseline interview, participants were stratified by age (below 50 and 50 and older) and randomized to receive one of three different brochures that differed only by whether they contained a gain, loss, or no message framing message (i.e., control). Thus, an approximately equal number of women below and above age 50 received a gain, loss, or no framing message. Women without a family history received the same brochure as their matched counterpart. All brochures emphasized the risks of getting breast cancer, the major risk factors (e.g., age, family history), the efficacy of mammography screening, and recommended screening guidelines. A copy of each brochure is provided in Appendix B. Along with the brochure was a letter informing women that they would be called within two weeks to get their impressions of the material.

Approximately two weeks after sending the brochures, participants were called by a trained telephone interviewer from the RCL. Participants were first queried as to whether they received the brochure. If not, they were sent a duplicate brochure –a maximum of two brochures per person. Those who acknowledged receipt of the brochure participated in a 15 minute interview. The questionnaire basically repeated the same questions posed during the baseline interview, along with questions about participants' opinions of the brochure. A copy of the three-month follow-up questionnaire is presented in Appendix C.

Lastly, participants were called 4 months after receiving the brochure for a final follow-up interview. This interview reassessed screening history and intentions to get a mammogram, pros and cons of screening, perceived risk of and worries about breast cancer, knowledge and attitudes towards genetic testing for breast cancer, and psychological well-being. Participants were paid \$10.00 for completing the final interview. The final questionnaire is presented in Appendix D.

Results

Overview: First discussed will be women reactions towards the intervention materials, and whether the gain and loss messages were perceived as intended. Discussion then centers on screening and factors related to screening such as intentions and stages of change. In these discussions, the effects of message framing are reviewed. The results then turn to women's attitudes towards having mammograms, how message framing affected these attitudes, and then whether attitudes predicted being on schedule. Subsequently, results are presented for perceptions of breast cancer risks and concerns, how these perceptions were affected by message framing, and whether these constructs predicted being on schedule. Results are then presented on

women's knowledge of breast cancer risk factors, and whether the intervention improved knowledge. Finally, results are presented concerning some exploratory data collected to assess women's desire to get tested for breast cancer susceptibility. In these presentations, the specific question in the analyses will be provided by using the question number as it appears in the baseline questionnaire (see Appendix A) which can then be matched to the corresponding questions in the three-month and final interview questionnaires. Since the demographic variables did not appreciably affect the main findings, they will not be discussed further.

Reactions to the Intervention Brochures

The gain/loss and control pamphlets were roughly evenly distributed among women with and without a family history of breast cancer. Among women with a family history, 43, 43, and 44 received the control, gain, and loss brochure, respectively; among women without a family history, 46, 47, and 43 received the control, gain, and loss brochure, respectively. Each matched pair received the same brochure (e.g., matched women with and without a family history received the same brochure).

During the three-month follow-up call, women were asked for their impressions of the gain, loss, or control brochures (see items 6.1-6.13). Bivariate relationships were first computed between message framing (gain/loss and control) and each reaction measure controlling for family history status. Message framing did not affect any of these outcomes. Of import, message framing did not affect whether women felt the brochure emphasized what they had to gain by getting regular mammograms or what they had to lose by not getting regular mammograms (items 6.2 and 6.3). Therefore, the brochures did not differentially effect perceptions of gains and losses as intended.

Bivariate relationships were then conducted among those who read the brochures to assess reactions to these materials as a function of family history status. These results are presented in Table 2. Overall, the majority read all of the brochure (62% to 66%). The brochure made women feel reassured, comforted, relieved, and did not induce fear, nervousness, or high levels of concern. However, women who did not have a family history of breast cancer felt less nervous and concerned after reading the brochure. The majority of women took interest in the brochure, and felt it was useful or very useful. In addition, the brochures either did not change or increased women's plans to get mammograms. The brochures also made women feel more likely to get breast cancer. In sum, while the brochures were not affective at manipulating women's perceptions of the gains and losses related to having or not having regular mammograms, the brochures did not arouse negative affect, were perceived as useful, increased the desire to get mammograms, and increased women's perceptions of their risks of getting breast cancer.

Screening History

Table 3 presents the screening history of women with and without a family history of breast cancer. Among women with a family history, 81% had ever had a screening mammogram – since controls were patients from the Duke Radiology Department, all had at least one screening mammogram. During the baseline interview, women 40 and older with a family history were less likely to have been on schedule than women without a family history (62% vs. 80%, $p < .004$). There were no differences in the proportion of women on schedule in either group, as a function of family history status, at the three-month and final follow-up. Subsequent bivariate analyses examined whether there were changes in the pattern of mammogram screening relative to the baseline interview among women 40 and older.

There were significant changes in screening patterns at the three-month follow-up relative to the baseline ($\chi^2_{(1)} = 6.4$ $p < .02$, based on McNemar's Test). Among women who were off schedule during baseline ($N=57$), 28% were now on schedule; among women who were on schedule during baseline, 13% were off schedule at the three-month follow-up. Inspection by family history status indicated that this change in screening occurred significantly more often among women with a family history ($\chi^2_{(1)} = 9.3$ $p < .002$, based on McNemar's Test). Among these women who were off-schedule during baseline ($N=36$), 33% were on schedule at the three-month follow-up, while among those who were on schedule at baseline ($N=59$), 8% were off-schedule at the three-month follow-up. Among women without a family history who were off-schedule at baseline ($N=21$), 19% were on schedule at the three-month follow-up, while among those who were on schedule at baseline ($N=86$), 16% were off-schedule at the three-month follow-up ($\chi^2_{(1)} = .09$, NS based on McNemar's Test).

Similarly, there were significant changes in screening patterns at the final follow-up relative to baseline ($\chi^2_{(1)} = 20.4$ $p < .001$, based on McNemar's Test). Among women who were off schedule during baseline ($N=55$), 47% were now on schedule; among women who were on schedule during baseline, 16% were off schedule at the final follow-up. Inspection by family history status indicated that this change in screening occurred for both women with and without a family history of breast cancer ($p < .004$). Among women with a family history who were off-schedule during baseline ($N=36$), 47% were on schedule at the final follow-up, while among those who were on schedule at baseline ($N=59$), 15% were off-schedule at the final follow-up. Among women without a family history who were off-schedule at baseline ($N=19$), 47% were on schedule at the final interview, while among those who were on schedule at baseline ($N=86$), 17% were off-schedule at the final follow-up.

With respect to having made an appointment to get a mammogram, very few women in both groups had an appointment at baseline ($\leq 13.0\%$). However, at the three-month and final follow-up, women without a family history were significantly more likely to have scheduled an appointment compared to women with a family history ($\chi^2_{(1)} = 5.1$, $p < .03$ and $\chi^2_{(1)} = 8.5$, $p < .004$, for the three-month and final follow-up, respectively).

Effects of Message Frame on Women's Mammography Screening

Bivariate relationships were computed first to assess whether being on schedule for having a mammogram among women 40 and older differed as a function of brochure at baseline, the three-month, and final follow-up. Overall, the proportion of women at baseline who were on schedule did not differ at baseline (70%, 75% and 70%, prior to being randomized to the control, gain, or loss brochure, respectively). Nor did the proportion of women who were on schedule differ at the three-month follow-up (66%, 71%, and 75% for the control, gain, or loss brochure, respectively) or at final follow-up (71%, 73%, and 77% for the control, gain, or loss brochure, respectively). Therefore, message framing had no effects on mammography screening.

Intentions to get Mammograms

Women both on and off schedule were asked if they were thinking and planning to have a future mammogram (see baseline items 1.4a,b; 1.5a,b; 1.6a,b; 1.7a,b) as a measure of intentions. Women 40 and older who were off schedule, were asked if they were thinking and planning to have a mammogram within the next three months; women 40 – 49 who were on schedule were asked if they were thinking and planning to have another mammogram within the next two years. Women 50 and older who were off schedule, were asked if they were thinking and planning to

have a mammogram within the next three months; Women 50 and older who were on schedule were asked whether they were thinking and planning to have another mammogram within the next year. These results are presented in Table 3. As an overall summary, a woman was classified as intending to get a mammogram if she said she was either thinking or planning to get a mammogram. Using this summary score, over 87% of women 40 and older were intending to get a mammogram across the three time points. Intentions did not differ among women with and without a family history across the three time points.

Subsequent bivariate analyses (McNemar's Tests) examined whether there were changes in the pattern of intentions relative to the baseline interview among women 40 and older. Overall, there were significant changes in intentions to get a mammogram from baseline to the three-month follow-up ($\chi^2_{(1)} = 36.0$ $p < .001$). Among women who were not thinking or planning to get a mammogram at baseline ($N=16$), 62% were thinking or planning to get a mammogram at the three-month follow-up; among women who were thinking or planning to get a mammogram ($N=186$), 9% were no longer thinking or planning to get a mammogram at the three-month follow-up. These changes in intentions from baseline to the three-month follow-up were found to be significant for women with and without a family history of breast cancer ($p < .001$).

Similarly, there were changes in intentions to get a mammogram from baseline to the final follow-up ($\chi^2_{(1)} = 54.3$ $p < .001$). Among women who were not thinking or planning to get a mammogram at baseline ($N=15$), 60% were thinking or planning to get a mammogram at the final follow-up; among women who were initially thinking or planning to get a mammogram ($N=183$), 4% were no longer thinking or planning to get a mammogram at the final follow-up. These changes in intentions from baseline to the final follow-up were found to be significant for women with and without a family history of breast cancer ($p < .001$). Message framing did not affect changes in intentions to get mammograms at either the three-month or final follow-up. In sum, intentions to get mammograms increased from the baseline to the 3-month and final follow-up. However, this was not due to the message framing interventions.

Intentions predicting having a mammogram on schedule

Analyses were conducted to assess whether intentions predicted being on schedule for women 40 and older during the three-month and final follow-up. Being on schedule was regressed onto baseline screening status (being on/off schedule) family history status, message framing (gain/loss/control), and baseline intentions in separate models. In none of these models did intentions predict being on schedule during the three-month or final follow-up [($OR_{(3\ month)} = 0.8$, $OR_{(final)} = 1.7$, NS)]. In all models, women who were on schedule during baseline were significantly more likely to be on schedule during the three-month and final follow-ups [($OR_{(3\ month)} = 23.9$, $OR_{(final)} = 5.5$, $p < .001$)]. Another set of logistic regression models were performed predicting being on schedule during the final follow-up. Being on schedule was regressed onto the three-month screening status (being on/off schedule) family history status, message framing (gain/loss/control), and intentions at three months. Intentions did not predict being on schedule during the final follow-up [($OR_{(final)} = 2.4$, $p < .11$)]. Women who were on schedule during the three-month follow-up were significantly more likely to be on schedule during the final follow-up [($OR = 13.2$, $p < .001$)]. Overall, intentions did not predict being on schedule.

Stage of Change

To obtain an overall summary that incorporated previous screening history and intentions, women 40 and older were categorized into one of the following mammography stages of change

according to the recommendations of Rakowski and colleagues (24, 25): precontemplators, contemplators, preparation, action, maintenance, relapse, and relapse risk. The algorithm to stage women is provided in Appendix E. The bottom of Table 3 presents the proportion of women in both groups distributed across these stages of change by interview. In general, the stage distributions across the three waves were similar for both groups of women, except for the final follow-up ($\chi^2_{(5)} = 11.7$ $p < .04$). Inspection of the stage distributions suggests that more women without a family history were in the preparation and relapse risk stages, while the majority of women with a family history were in the contemplation stage. Of note, compared to the baseline, there were significant increases in the number of women in the action stage at the three-month and final follow-up. Since the staging algorithm incorporates screening history, analyses between stage and subsequent screening were not conducted. In addition, although an aim of this proposal was to assess whether gain and loss messages would be differentially effective for women in the precontemplation and contemplation stages, due to the small number of women in these stages, this precluded conducting a formal test of this hypothesis.

Attitudes Towards Mammography Screening

Attitudes towards mammography were assessed primarily via the use of the pros and cons (questions 4.1 - 4.11), attitudinal ambivalence (item 4.12), perceived effectiveness of mammography at detecting breast cancer early (item 4.13), and a global question assessing participant's overall attitude towards having a mammogram (question 4.14). Alphas for the pros were .73, .76, and .79 at the baseline, three-month, and final follow-up, respectively. Alphas for the cons were .61, .62 and .69 at baseline, three-month, and final follow-up, respectively.

A 2 (family history status) x 3 (message framing: gain/loss/no message) x 3 (wave: baseline, three-month, and final follow-up) mixed model ANOVA was conducted to assess women's perceptions of the pros and cons of mammography use. With respect to the pros, there was a significant main effect for wave [$(F(2,248) = 5.7, p < .004)$], as well as two significant two-way interactions: 1) a wave by family history status interaction [$(F(2,248) = 5.80, p < .004)$, and 2) a message framing by family history status interaction [$(F(2,249) = 5.8, p < .004)$]. The main effect for wave revealed significant increases in the perceived pros from baseline to the three-month and final follow-up ($M = 21.25$ vs. 21.77 vs. 21.77 for the baseline, three-month and final follow-up, respectively). There were no significant mean differences in the pros at the three-month and final follow-up. The wave by family history interaction revealed that mean changes in the pros occurred for women with a family history [$(F(2,124) = 10.3 p < .001)$], but not among women without a family history [$(F(2,127) < 1)$]. Among women with a family history, pros increased from baseline to the three-month and final follow-up family history [$(M_{(base)} = 20.80, M_{(3\ month)} = 21.94, M_{(final)} = 21.54, ps < .008$ for contrasts] but not among women who did not have a family history ($M_{(base)} = 21.70, M_{(3\ month)} = 21.60, M_{(final)} = 21.96$). Among women with a family history, there were no significant mean difference in pros between the three-month and final follow-up.

The message framing by family history status interaction occurred only for the final follow-up. Contrasts revealed that women without a family history who received gain messages had higher perceived pros compared to women with a family history who received gain messages ($M = 22.62$ vs. $20.62, p < .003$). In addition, among women with a family history, there was a higher pro score associated among women who received no gain/loss message (i.e., control) or a loss than those who received a gain message ($M_{(cont)} = 22.1, M_{(loss)} = 21.9$ vs $M_{(gain)} = 20.6, ps < .02$). No other effects were found.

With respect to the cons, there emerged a significant wave main effect only [$F(2, 248) = 4.0, p < .02$]. Subsequent contrasts revealed that the mean con score at the three-month and final follow-up decreased relative to the baseline score [$M_{(base)} = 14.36, M_{(3 \text{ month})} = 13.71, M_{(final)} = 13.88, ps < .04$]. The mean con score did not differ between the three-month and final follow-up. No other significant effects were found.

Additional analyses were conducted to assess whether the other attitudinal variables (i.e., ambivalence, mammograms are effective, and overall attitudes towards mammograms) changed across time as a function of family history status, message framing, and their interactions. Based on a 2 (family history status) x 3 (message framing: gain/loss/control) x 3 (wave: baseline, three-month follow-up, and final follow-up) mixed model ANOVAS, there emerged a significant main effect for wave for feeling ambivalent about getting mammograms [$F(2, 241) = 4.9, p < .008$]. Subsequent contrasts revealed the mean ambivalence decreased from baseline to the three-month follow-up ($M = 1.99$ vs. $1.79, F(1, 242) = 9.7, p < .001$). However, neither the mean felt ambivalence at baseline or at the three-month follow-up differed significantly from the mean level of ambivalence at the final follow-up ($M = 1.87$). Similarly, there was a significant main effect for wave for how favorable women viewed mammograms [$F(2, 241) = 10.6, p < .0001$]. Subsequent contrasts revealed that compared to their baseline, women had more favorable attitudes towards mammograms at the final follow-up [$M = 4.08$ vs. $4.31, F(1, 242) = 18.2, p < .0001$]. There were no effects for family history, message framing, or wave for how effective women viewed mammograms at baseline and at the three-month follow-up ($M = 3.28$ vs. 3.37 for the baseline and three-month follow-up, respectively).

It was of interest to assess whether these attitudinal variables predicted being on schedule and the intention to have a future mammogram. It was predicted that a greater number of pros, less cons, lower attitudinal ambivalence, viewing mammograms as effective, and having a more positive attitude towards mammography screening would be related to being on schedule and thinking of getting a mammogram in the future. To test these predictions, logistic regression analyses were conducted predicting these two outcomes from each attitudinal variable separately. The reference groups were the odds of being off schedule and not thinking of getting another mammogram. Overall none of the attitudinal variables predicted being on schedule. Similarly, only one of the attitudinal variables predicted thoughts about having a future mammogram. Women with more positive attitudes were less likely not to have thought about getting a future mammogram ($OR = .72, p < .05$).

Attitudes predicting having a mammogram on schedule

The first set of analyses examined whether the pros and cons predicted being on schedule for women 40 and older during the three-month and final follow-up. Being on schedule was regressed onto baseline screening status (being on/off schedule) family history status, message framing (gain/loss/control), and baseline pros and cons in separate models. In none of these models did the pros predict being on schedule during the three-month or final follow-up [$(OR_{(3 \text{ month})} = 1.0, OR_{(final)} = 1.2, NS)$]. However, women who expressed more cons at baseline were less likely to be on schedule during the three-month follow-up [$(OR = .89, p < .03)$] and at the final follow-up [$(OR = .89, p < .02)$]. In all models, women who were on schedule during baseline were significantly more likely to be on schedule during the three-month and final follow-ups [$(OR_{(3 \text{ month})} = 24.5, OR_{(final)} = 6.3, ps < .001)$]. Another set of logistic regression models were performed predicting being on schedule during the final follow-up. Being on schedule was regressed onto the three-month screening status (being on/off schedule), family history status, message framing (gain/loss/control), and the pros and cons at three months in separate models. In

this model the pros did not predict being on schedule during the final follow-up [$OR_{(final)} = 1.1$, NS]. However, women who expressed more cons at the three-month follow-up were less likely to be schedule during the the final follow-up ($OR = .86$, $p < .005$). In all models, women who were on schedule during the three-month follow-up were significantly more likely to be on schedule during the final follow-up ($p < .001$). Thus, among the pros and cons, only the cons significantly predicted being on schedule.

Another set of logistic regression analyses were conducted to assess whether the other attitudinal constructs (i.e., ambivalence, perceived effectiveness of mammograms, and overall attitudes) predicted being on schedule during the three-month and final follow-up. Being on schedule was regressed onto baseline screening status (being on/off schedule) family history status, message framing (gain/loss/control) and each of the attitudinal constructs in separate models. Ambivalence at baseline did not predict being on schedule during the three-month ($OR = .69$, $p < .04$) or final follow-up ($OR = .77$, NS). Similarly, whether a women viewed mammograms as effective did not predict being on schedule during the three-month ($OR = .94$) or final follow-up ($OR = .97$). However, women who had more favorable attitudes towards mammograms were more likely to be on schedule during the final ($OR = 1.88$, $p < .006$) but not the three-month follow-up ($OR = 1.61$). In all the aforementioned models, being on schedule during the baseline predicted being on schedule during the three-month and final follow-up (Odds ratios ranged from 5.0 to 23.3, $p < .001$). Another set of logistic regression models were performed predicting being on schedule during the final follow-up from data gathered during the three-month follow-up. Women who felt more ambivalent at three months were significantly less likely to be on schedule during the final follow-up ($OR = .64$, $p < .04$). Similarly, women who had more favorable attitudes towards mammograms at the three-month follow-up were significantly more likely to be on schedule during the final follow-up ($OR = 1.99$, $p < .004$). Whether a women viewed mammograms as effective did not predict being on schedule during the final follow-up ($OR = 1.34$).

Perceived Risks of and Concerns about getting Breast Cancer

It was expected that women with a family history would express greater comparative risk (i.e., own risk vs. women their age and sex; item 6.1) and lifetime risk (item 6.2), and more concerns (item 6.4) about getting breast cancer than women without a family history. It also was predicted that comparative risk, perceived lifetime risk, and concerns about getting breast cancer would be positively related. There results are presented in Table 4.

Overall these predictions were confirmed. Women with a family history felt greater comparative and lifetime risk than women without a family history across all three waves ($p < .001$). Moreover, women with a family history felt more concerned about getting breast cancer than women without a family history across all three waves ($p < .004$). There were no differences in perceptions of risk and concerns as a function of message framing, nor did message framing interact with family history status or wave to affect changes in perceptions of risk and concerns.

Perceived risks and concerns predicting having mammograms on schedule

Logistic regression models were performed predicting being on schedule during the three-month and final follow-up for women 40 and older. Being on schedule was regressed on baseline screening status (being on/off schedule) family history status, message framing (gain/loss/control), and absolute risk, comparative risk and concerns in separate models. In none

of these models did risks or concerns predict being on schedule during the three-month or final follow-up (Odds ratios ranging from .95 to 1.2). However, women who were on schedule during baseline were significantly more likely to be on schedule during the three-month and final follow-ups (Odds ratios ranging from 5.9 to 22.1, $p < .001$). Another set of logistic regression models were performed predicting being on schedule during the final follow-up. Being on schedule was regressed onto the three-month screening status (being on/off schedule), family history status, message framing (gain/loss/control) and absolute risk, comparative risk and concerns from the three-month interview in separate models. In none of these models did risks or concerns predict being on schedule during the final follow-up (Odds ratios ranging from .77 to 1.3). However, women who were on schedule during the three-month follow-up were significantly more likely to be on schedule during the final follow-up (Odds ratios ranging from 14.1 to 15.4, $p < .001$). While an aim of the study was to assess whether risks interacted with message framing to predict screening, since message framing was not deemed effective, these analyses were not conducted.

Attributions of Risk

To understand further the underlying causes of women's own perceptions of lifetime risk, participants were asked why they rated their risk as they did (item 6.3). Responses were categorized into one of the categories used by Aiken and colleagues (26), based on Weinstein's (27) scheme: personal actions (e.g., diet, exercise), heredity (e.g., family history), physiological (e.g., age), environmental (e.g., chemicals in food), psychological (e.g., optimism), chance, and other. Three different strategies were used to assess the relationships between attributions of risk and perceived risk. First, we examined the pattern of relationships between attributional domains and women's ratings of their risk, controlling for family history status. Second, we examined whether women with and without a family history differed in the frequency with which they mentioned a specific category. Third, we examined whether family history status interacted with attributional domains to predict perceptions of risk. Since environmental, psychological, and chance causes were mentioned by less than 1% of the participants, these domains will not be discussed further.

There were no significant overall bivariate relationships between risk perceptions and heredity and physiological causes. However, women who reported personal action causes were significantly more likely to report less risk than women who did not mention personal action causes ($\chi^2_{(1)} = 20.1$, $p < .001$ for trend). Taking into account family history status, women with rather than without a family history of breast cancer were more likely to mention heredity causes (66.9% vs. 47.7%, $\chi^2_{(1)} = 9.9$, $p < .002$), and less likely to mention physiological (22.3% vs. 34.8%, $\chi^2_{(1)} = 4.9$, $p < .03$) and personal action causes (16.9% vs. 52.2%, $\chi^2_{(1)} = 36.4$, $p < .001$). The pseudo-homogeneity statistic, which tests whether the homogeneity of effect sizes between attributions of risk and perceived risk differ by strata, revealed that the relationship between perceived risk and heredity differed by family history status ($\chi^2_{(1)} = 17.5$, $p < .001$). Women with a family history who mentioned heredity causes (e.g., having a family history of breast cancer) were more likely to report greater risk ($\chi^2_{(1)} = 17.5$, $p < .001$). Among women without a family history, there was no relationship between the mentioning of heredity causes (e.g., not having a family history) and perceived risk ($\chi^2_{(1)} = 2.6$, $p > .10$).

Knowledge of Breast Cancer Risk Factors as a Function of Family History Status

It was predicted that knowledge of breast cancer risk factors would be low. Degree of knowledge was scored as follows: a correct response to each of the nine potential risk factors received a score of 1; incorrect or "don't know" responses received a score of 0 (see baseline items 5.1-5.9). A similar coding was used for the three-month follow-up. The percentage of correct responses to each of the knowledge items by family history status is presented in Table 5.

Inspection of Table 5 reveals that at baseline, women with and without a family history had poor knowledge of breast cancer risk factors. Less than 50% of women in both groups correctly knew that growing older, having no children or having the first child after age 30, late age of menopause, early menarche, and never having breastfed were related to an increased breast cancer risk. Furthermore, only 42% knew that stress was not related to breast cancer risk, and 28% knew that injury to the breast(s) did not increase breast cancer risk. However, a high proportion of women in both groups (> 88%) correctly mentioned family history as a risk factor. Subsequent chi-square tests revealed no significant differences in proportions of correct responses to each knowledge item between women with and without a family history of breast cancer. Creating a total knowledge score by summing across items revealed that both groups of women correctly identified a median of three items.

At the three-month follow-up, there were significant increases in the proportion of correct responses. Indeed, the median correct responses was four compared to three at baseline. There were no significant difference in the proportion of correct responses to each comparing women with and without a family history for all risk factors except for the item pertaining to having a breast injury. Women with a family history were more likely to correctly state that having a breast injury (e.g., bruise) did not increase one's risk of getting breast cancer compared to women without a family history ($\chi^2_{(1)} = 5.2$, $p < .03$).

Subsequent bivariate analyses (McNemar's Tests) examined whether there were changes in the number of correct and incorrect responses. Overall, increases in the proportion of women with and without a family history who gave a correct response increased for four out of the six knowledge items: age as risk factor, stress, family history, and realizing that having children at a later age (after 30) increased one's risk. The proportion of women who at baseline gave an incorrect response but then gave correct responses at the three-month follow-up was 51% for age as a risk factor, 58% for family history status, 43% for stress, and 43% for having a first child after the age of 30 ($p < .05$). In addition, the proportion of women with a family history who gave a correct response to acknowledging that injury to the breast did not lead to breast cancer, and that never having a child leads to greater risk, increased 40% and 36%, respectively ($p < .05$). Among women without a family history, there were no significant changes in the proportion of correct responses at the three-month follow-up for these two knowledge questions. In sum, there was improvement in knowledge among the majority of knowledge items.

Relationship between Knowledge of Risk Factors and Perceptions of Risk

Spearman correlations were conducted to assess relationships between the total knowledge score and perceived breast cancer risk and concern by group. At baseline, among women with a family history, those who had more knowledge reported greater comparative risk ($r = .28$, $p < .002$) and felt more concerned about getting breast cancer ($r = .23$, $p < .009$). Knowledge was unrelated to absolute risk ($r = .13$). Among women without a family history, knowledge was unrelated to perceived comparative risk, absolute risk, or concerns about getting breast cancer ($r = .01$, $.16$ and $.15$, respectively). At the three-month follow-up, women with a family history who

had more knowledge, reported greater comparative risk ($r = .26$, $p < .03$), and breast cancer concerns ($r = .26$, $p < .004$) but not greater absolute risk ($r = .17$, $p < .06$). Among women without a family history, knowledge was unrelated to perceptions of absolute risk ($r = .04$), comparative risk ($r = .03$), or breast cancer concerns ($r = -.06$).

Effects of Message Framing on Overall Knowledge of Breast Cancer Risk Factors

A 2 (family history status) x 3 (message framing: gain/loss/control brochures) x 2 (wave: baseline, three-month follow-up) mixed ANOVA was performed to assess whether there were any changes in mean level of knowledge using the six knowledge items that were common to both questionnaires at baseline and at the three-month follow-up. Overall, there was a significant main effect for wave only ($F(2, 260) = 101.28$, $p < .0001$). Compared to their baseline scores, women at the three-month follow-up increased their average understanding of breast cancer risk factors ($M = 2.65$ vs. 3.61 , for the baseline and three-month follow-up, respectively).

Predictors of genetic testing

With the growing advances and interests among women about genetic testing for breast cancer (e.g., BRCA1), for exploratory reasons, analyses were performed predicting interest in genetic testing among these two populations (item 6.4). A-priori it was expected that women with a family history would be most interested in genetic testing, and that women who reported greater risk, as well as greater concerns about breast cancer, would be most interested in having genetic testing for breast cancer. These results were confirmed in all bivariate analyses. However, in multivariate analyses, only being very concerned about getting breast cancer predicted greater interest in testing compared to women who were not at all concerned. These results are reported in the attached manuscript which is currently, in press, at the journal, Cancer Epidemiology, Biomarkers, and Prevention.

At the final follow-up, women were asked again for their interest in genetic testing, along with their knowledge about BRCA1 and BRCA2, reasons for wanting to be tested, and likelihood of having a mutation. These results are currently being assessed, and should be written as a paper during the Summer of 1999.

Conclusions

This study had several aims. A major aim was to compare African-American women with and without a family history of breast cancer with respect to mammography screening, attitudes towards mammography screening, perceptions of risk and concerns about breast cancer, and knowledge concerning breast cancer risk factors. To date, assessing these constructs simultaneously among a matched cohort has been lacking. A second major aim of this study was to assess whether message framing had a significant effect on the aforementioned constructs, and whether the presumed effectiveness differed by family history status and stage of change. This discussion will focus on the first aims, and then discuss the effects of our message framing brochures. We will end with potential weakness of the study and overall conclusions.

Mammography screening, intentions, attitudes, risk and knowledge.

With respect to having a mammogram, there was generally good compliance with screening. For example, adherence to screening guidelines (i.e., being on schedule) was relatively high (e.g., over 61%). These results compare favorably with national estimates of recent screening

among African-Americans of 32% (3). Of import, there were significant changes in the pattern of screening. There was a greater proportion of women with a family history who went from being off schedule at baseline to being on rather than off schedule at the three-month and final follow-up. A similar profile occurred for women without a family history at the final follow-up. Moreover, at the three-month and final follow-up, women without a family history were more likely to have scheduled an appointment to get a mammogram than women with a family history. This may be a reflection of the Duke Radiology Department reminding women who have had a previous mammogram to get another. It is also possible that once women start a routine of getting mammograms, they are more likely to take the initiative to schedule another mammogram.

The majority of women 40 and older both on and off schedule expressed strong intentions (i.e., thinking and/or planning) to get mammograms, and level of intentions did not differ between women with and without a family history of breast cancer. As with mammogram screening, intentions increased among women who initially were not intending to get mammograms. Of note, intentions did not predict future screening practices when controlling for previous screening rates and experimental conditions. Indeed, whether or not a woman had a previous mammogram was the strongest predictor of whether she was on schedule during the next follow-up period.

Comparisons were made among these two populations concerning their attitudes towards mammography use. In general, the pros for mammography screening increased from baseline to the three-month and final follow-up. Conversely, the cons decreased from the baseline to the three-month and final follow-up. In addition, relative to baseline, there were reduced feelings of ambivalence towards getting mammograms at the three-month follow-up, and generally, women expressed more favorable attitudes towards mammography at the final follow-up. In sum, the gestalt that emerged was that women's evaluations of mammography increased, and these results were not due to any differential component of the intervention (e.g., message framing).

The most consistent and powerful set of findings emerged in the area of risk perceptions and concerns about getting breast cancer. Consistent with predictions, women with a family history of breast cancer reported greater comparative and absolute risk, and felt more concerned about getting breast cancer than women without a family history. Thus, this is the first study using a fairly large number of women with and without a family history, to document that risk perceptions and concerns about breast cancer do differ among these two populations.

Along with measuring risk, this study examined women's attributions for their perceived lifetime risk. Of import, neither heredity or physiological causes were related to perceptions of risk as main effects. Rather personal action causes (e.g., diet, exercise, smoking, getting mammograms, etc.) was the only attributional correlate of risk. Given that most women (e.g., 90%) acknowledged that having a family history is related to increased risks, it was unanticipated that heredity causes were unrelated to perceived risk. However, this conclusion needs to be tempered by the fact that heredity did predict perceptions of risk only among women with a family history. These results have two implications. First, women may experience heightened and unwarranted levels of risk if they believe that the performance of detrimental behaviors (e.g., smoking, do not exercise) put them at higher risk. Although these behaviors may ultimately become part of the calculation of a woman's chances of getting breast cancer (e.g., Gail et al. algorithm), to date this is not the case. Second, the linkage between risk and family history status needs to be emphasized. In sum, there needs to be continued attention given to educating African-American women about breast cancer risk factors.

The suggestion that further education is warranted was well supported by the poor level of knowledge concerning breast cancer risk factors. At baseline, women with and without a family history had poor working knowledge of breast cancer risk factors; indeed, the mean number of correct responses was about three. Among the various risk factors, less than half knew that getting older is related to heightened risk of breast cancer. Moreover, a substantial proportion of women in both groups believed incorrectly that stress and bruising of the breast(s) are related to getting breast cancer. These results point to the need for continued efforts to educate women about the importance of age as a risk factor for breast cancer and to correct inaccuracies. Fortunately, overall knowledge at follow-up improved significantly. Compared to baseline, there were significant improvements among all women at correctly relating age, family history, having a child after age 30, and stress to breast cancer risk. Of import, knowledge improved for all six items among women with a family history. These results attest that our brochures, which discussed these issues, were effective. However, overall knowledge was weakly related to perceptions of risk and concerns, and did not predict screening. Therefore, future research should evaluate under what circumstances knowledge of breast cancer risk factors predict most strongly risk perceptions and concerns.

Message framing

This study assessed the extent to which framing messages about mammography as gains or losses affected screening and attitudes. An assessment of women's reactions to the different brochures indicated that they were well-received and read by the majority of women (e.g., useful, informative). However, when queried, women who received the gain or loss message did not perceive the brochures as emphasizing either what a woman has to gain by having mammograms or what a woman stands to lose by not getting mammograms. Thus, it is unlikely that our message-framed brochures were perceived as intended. Consequently, the lack of a relationship between message framing and mammography screening, intentions, attitudes, risk, and knowledge may simply be due to women reacting to these brochures similarly. It might be worthwhile for future researchers to create messages that more vividly portray the gains and losses to more fully capture women's attention to these issues.

Cautionary notes pertaining to the study design

The reader should be aware of several caveats in interpreting our results. First, our controls were obtained from a Radiology Department. It is unclear how our results would have differed if the women without a family history were obtained from a random community sample. Although attempts were made to match women with respect to mammography screening history, this was not achieved fully. Therefore, comparisons between these two groups on factors related to screening may unduly inflate how well women without a family history are doing with respect to screening. In addition, most of our attitudinal variables were assessed using single items. This raises the question of item reliability and validity. Given that several constructs needed to be assessed, we felt that using items that best reflected the construct of interest given the exploratory theme of this proposal. Indeed, due to time constraints, and to lessen respondent burden, we did not assess mammography processes of change as initially expected. Furthermore, we only assessed mammography screening patterns with an average of seven months post-baseline. Such a narrow timeframe limited our ability to assess large changes in the variability of screening, and to more powerfully assess how several of our constructs would have predicted

such variability. Indeed, almost all the attitudinal variables, intentions, risk perception and knowledge items failed to predict screening behavior when controlling for baseline screening.

Conclusions

There have been no published studies that compare African-American women with and without a family history with respect to screening histories, attitudes towards mammography, perceived risk and breast cancer concerns, and knowledge of risk factors. These results suggest that screening rates among both groups of women are roughly comparable, that both hold strong intentions to get mammograms, have similar attitudes towards getting mammograms, and that both have equally poor knowledge of breast cancer risk factors. The main difference is that women with a family history correctly see themselves at higher risk and are more concerned about getting breast cancer. Unfortunately, the provision of the gain or loss messages was not perceived as intended, and thus may account for their lack of differentially affecting several of the study's outcomes. However, our brochures did serve to increase knowledge and enhance attitudes towards mammography screening independent of message framing. Future research should: 1) design more effective gain and loss framed messages, and 2) use a similar cohort of women and track for a longer period of time their patterns of screening, attitudes, knowledge of breast cancer risk factors, and perceptions of risks and concerns.

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Table 1

Study population characteristics.

<u>Characteristic</u>	<u>Baseline</u>		<u>3 month Follow-up</u>		<u>Final Follow-up</u>	
	<u>Cont.</u>	<u>Fam.</u>	<u>Cont.</u>	<u>Fam.</u>	<u>Cont.</u>	<u>Fam.</u>
Mean Age	50.4	48.8	50.3	48.8	49.9	49.1
SD	12.9	13.3	12.9	13.4	12.8	13.3
<u>Education</u>						
High school or less	35.8	32.3	35.9	32.8	35.9	32.5
Trade or technical school	14.9	8.5	14.5	8.6	14.8	8.7
Some college	23.8	30.8	23.7	29.7	23.4	29.4
College graduate	14.2	13.8	14.5	14.1	14.8	14.3
Graduate work or degree	11.2	14.6	11.4	14.8	10.9	15.1
<u>Marital Status</u>						
Single	19.1	18.5	19.6	18.0	19.4	19.4
Married or living as married	50.7	43.1	51.1	43.8	52.5	43.6
Widowed	8.1	15.4	8.3	14.8	7.8	15.1
Divorced	13.9	19.2	12.8	19.5	12.4	19.8
Separated	8.1	3.8	8.3	3.9	7.8	4.0
<u>Work status</u>						
Working full-time	56.6	55.4	56.4	55.5	58.1	55.6
Working part-time	5.9	13.8	6.0	14.1	5.4	14.3
Full-time homemaker	4.4	4.4	4.5	4.7	3.9	4.8
Retired	19.8	16.2	19.6	15.6	20.2	15.9
Unemployed	2.2	3.1	2.3	3.1	2.3	3.2
Other	11.0	6.9	11.3	7.0	10.1	6.4
Has no insurance coverage	4.4	8.5	4.6	7.8	4.7	7.1

Note. There were 136, 133, and 129 women without a family history at baseline, the three-month follow-up and at final follow-up, respectively. There were 130, 128, and 126 women with a family history at baseline, the three-month follow-up, and at final follow-up, respectively. As expected, there were no significant differences in mean age between the controls and women with a family history; thus the matching based on age was deemed successful.

Cont. = Women without a family history

Fam. = Women with a family history

Table 2

Reactions to the Brochures

<u>Measure</u>	<u>Family History</u>	<u>Controls</u>	<u>X²</u>
How much of the brochure did you read?			
None of it	7.8	12.8	
Some of it	10.2	12.0	
Most of it	15.6	12.8	
All of it	66.4	62.4	.94
Did the brochure make you feel...			
Not at all scared	61.0	69.0	
Slightly scared	16.9	14.7	
Somewhat scared	19.5	12.9	
Scared	2.5	1.7	
Very Scared	0.0	1.7	1.60
Did the brochure make you feel...			
Not at all reassured	4.4	7.8	
Slightly reassured	8.8	10.3	
Somewhat reassured	20.2	26.7	
Reassured	50.0	32.8	
Very reassured	16.7	22.4	.71
Did the brochure make you feel...			
Not at all nervous	62.7	77.6	
Slightly nervous	20.3	10.3	
Somewhat nervous	11.9	9.5	
Nervous	3.4	1.4	
Very nervous	1.7	0.9	5.53*
Did the brochure make you feel...			
Not at all comforted	7.7	8.8	
Slightly comforted	11.1	8.8	
Somewhat comforted	23.9	26.6	
Comforted	40.2	38.0	
Very comforted	17.1	17.7	0.00
Did the brochure make you feel...			
Not at all concerned	13.6	27.6	
Slightly concerned	13.6	11.2	
Somewhat concerned	11.9	25.0	
Concerned	36.4	18.1	
Very concerned	24.6	18.1	9.45**

Table 2 continues

Table 2 continued

Reactions to the Brochures

<u>Measure</u>	<u>Family History</u>	<u>Controls</u>	<u>χ^2</u>
Did the brochure make you feel...			
Not at all relieved	10.4	15.6	
Slightly relieved	15.6	8.7	
Somewhat relieved	21.7	26.1	
Relieved	36.5	33.0	
Very relieved	15.6	16.5	.06
How interested were you in the brochure?			
Not at all interested	0.0	0.9	
Slightly interested	5.1	1.7	
Somewhat interested	10.2	6.0	
Interested	30.5	32.8	
Very interested	54.2	58.6	1.01
Was the information in the brochure personally useful to you. Would you say...			
Not at all useful	0.8	0.0	
Slightly useful	4.2	3.4	
Somewhat useful	11.0	14.7	
Useful	40.7	31.9	
Very Useful	43.2	50.0	.50
To what extent did the brochure affect your plans to get a mammogram.			
Made you feel less likely	0.9	0.9	
Did not change your plans	46.6	41.4	
Made you feel more likely	52.5	57.8	.65
To what extent did the brochure affect how you see your chances of getting breast cancer.			
Made you feel less likely	11.0	11.2	
Did not change your feelings	17.8	14.7	
Made you feel more likely	71.2	74.1	.43

Note. Numbers represent rounded row percentages. Analyses excluded women who did not read the brochure (N=27).

* p<.05.

** p<.01.

Table 3

Mammography screening history among women with and without a family history of breast cancer.

<u>Screening Variable</u>	<u>Baseline</u>		<u>Three Month Follow-up</u>		<u>Final Follow-up</u>	
	<u>Fam</u>	<u>Cont</u>	<u>Fam</u>	<u>Cont</u>	<u>Fam</u>	<u>Cont</u>
Ever had a mammogram	81.5	99.3	84.6	99.3	85.7	100.0
On schedule ^a	61.8	80.0**	69.5	71.0	76.7	70.5
Think and/or planning to get a Mammogram.	92.7	91.7	87.8	89.5	92.2	93.7
Has made an appointment for a Mammogram	12.4	9.1	8.4	19.6*	13.7	31.1**
<u>Stages of change</u>						
Precontemplators	1.0	0.0	2.1	0.0	0.0	0.0
Contemplators	22.7	13.6	21.0	17.8	23.2	12.6
Preparation	12.4	9.1	8.4	19.6	13.7	31.0
Action	13.4	20.0	51.6	45.8	35.8	32.0
Maintenance	44.3	48.2	8.4	6.5	21.0	16.5
Relapse Risk	1.0	3.6	3.2	2.8	2.1	4.8
Relapse	5.2	5.4	5.3	7.5	4.2	2.9

Note. Percentages represent row percentages (e.g., among women with a family history of breast cancer, 91.7% ever had a mammogram) except for stages of change whereby percentages represent column percentages (among women with a family history, 1% were precontemplators). Stages of change were calculated for women 40 and older. There were 111 and 97 women ages 40 and older with and without a family history of breast cancer.

^a Women 40–49 were considered being on schedule if they had a mammogram within 2 years of the baseline telephone interview. Women 50 and older were considered being on schedule if they had a mammogram within a year of the baseline interview.

^b Women 40 and older who were not on schedule were asked if they were thinking about having or planning to have a mammogram within the next 3 months.

Table 4

Perceptions of Breast Cancer Risks and Concerns by Family History Status

<u>Characteristic</u>	<u>Baseline</u>		<u>3 month Follow-up</u>		<u>Final Follow-up</u>	
	<u>Cont.</u>	<u>Fam.</u>	<u>Cont.</u>	<u>Fam.</u>	<u>Cont.</u>	<u>Fam.</u>
Perceived lifetime risk	2.72	3.42	2.78	3.63	2.52	3.50
Perceived comparative risk	2.66	3.21	2.75	3.53	2.75	3.56
Concerns about getting breast cancer	2.92	3.39	2.77	3.48	3.02	3.48

Table 5

Proportion of Correct Responses to the Breast Cancer Knowledge Items by Family History Status.

<u>Knowledge item</u>	<u>Baseline</u>		<u>Three Month Follow-up</u>	
	<u>Controls</u>	<u>Family History</u>	<u>Controls</u>	<u>Family History</u>
Being older	44.8	43.8	61.6	67.2
Having a family history of breast cancer	90.4	88.5	91.7	92.2
Having lots of stress	41.9	40.8	56.4	55.5
Having a breast injury	27.9	33.9	39.1	53.1
Being older when you have your first Child	31.6	42.3	58.6	55.5
Never having had children	20.6	23.1	45.9	46.8
Late age of menopause	39.0	28.5	---	---
Early age of starting periods	22.1	18.5	---	---
Never having breastfed	17.0	21.5	---	---
Mean correct responses	2.58	2.72	3.53	3.70
Median correct responses	2.00	3.00	4.00	4.00

Note. Percentages represent the proportion of women who correctly identified each variable as a possible risk factor. For having a breast injury or lots of stress, the numbers represent the proportion of women who knew that having a breast injury or lots of stress is not related to an increased risk of breast cancer. Late age of menopause, early stage of starting periods, and never having breastfed were not discussed as part of the brochures and, therefore, were not asked at the three-month follow-up.

Presentations and Papers

Lipkus, I.M., & Terreniore, J. (October/November, 1997). Mammography screening and perceived risk of breast cancer among African-American women with a family history of breast cancer. The Department of Defense Breast Cancer Research Program Meeting, Era of Hope. Washington, D.C.

Lipkus, I.M., Iden, D., Terrenoire, J., & Feaganes, J.R. (in press). Relationships among Breast Cancer Concern, Risk Perceptions and Interest in Genetic Testing for Breast Cancer Susceptibility among African-American Women with and without a Family History of Breast Cancer. Cancer Epidemiology, Biomarkers and Prevention.

Personnel Funded By the Grant

Isaac Lipkus	Principal Investigator
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Deborah Iden	Project Manager
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Karen Ellis	Secretary/Support Staff
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Appendix A

Baseline Telephone Interview Questionnaire

NAME OF FIRST DEGREE RELATIVE: _____

NAME OF AND RELATIONSHIP TO BC PT.: _____

DATE OF INTERVIEW: ____/____/____ INTERVIEWER INITIALS: _____

INTRODUCTION TO QUESTIONNAIRE

Hello, my name is _____, and I'm calling for Dr. Isaac Lipkus at the Comprehensive Cancer Center at Duke Medical Center. Recently we sent you a letter about a project we are conducting with African-American women about mammograms and breast cancer screening.

If you have a minute I'd like to briefly review what our study is about. The goal of this study is to learn how to motivate African-American women to get mammograms. We are in the process of asking women (who have never had breast cancer) with and without a family history of breast cancer to be part of this important project. Your **[RELATIVE: MOTHER, SISTER, DAUGHTER], [NAME OF RELATIVE]**, has given us permission to contact you to see if you would be willing to participate. Before I go any further I need to ask you a question:

Has a doctor ever told you that you have breast cancer?

1. Yes 2. No 7. Refused 8. Don't know

[IF ANSWER IS YES, HAS HAD BREAST CANCER]: I'm very sorry to hear that. We would like to be able to contact your first degree female blood relatives (that is your mother and any sisters or daughters that you have) to see if they would be interested in being part of our project. In order to do that, we will need your permission; are you willing to allow us to contact them?

Yes No

[IF YES, WILLING TO PROVIDE RELATIVE INFO]: Thank you very much for your help. Before we can write down the information about your relatives, we must obtain what is known as "informed consent" from you. This involves reading you a brief statement describing the project over the phone; it takes only about a minute or so. Then if you agree we'll go ahead and write down the information we need on your female relatives. And finally we will send you a copy of the form we read to you so that you can have it for your records. **[READ CONSENT FORM AND OBTAIN VERBAL CONSENT, THEN GET RELATIVE INFO.]**

[IF NO, REFUSES TO PROVIDE INFO]: For our records, we would like to better understand why women are reluctant to give us the names of their relatives. This can help us improve our project. Is there any reason why you would not like us to have the names and addresses of your relatives?

[REASON FOR REFUSING]: _____

[CLOSING 1:] Thank you very much for your time; I'm sorry to have bothered you. Please feel free to call Dr. Lipkus or Jenny Terrenoire at 919-956-5644 if you have any questions about the

project. Goodbye.

[IF ANSWER IS NO, NEVER HAD BREAST CANCER]: The project will take very little time and effort. You will be asked a few questions about breast cancer screening and will be mailed a short brochure about mammograms and breast cancer. This would involve taking part in 3 telephone interviews, each lasting about 15-20 minutes. The project will take a total of about 1 hour of your time over a period of approximately one year, and you will be paid \$20.00 for your participation. Do you have any questions?

Are you willing to participate? Yes No

[IF REFUSES TO GIVE CONSENT]: For our records, we would like to better understand why women do not wish to be part of our study; this information could help us improve our project. Is there any reason why you don't want to participate?

[REASON FOR REFUSING]: _____

We are also interested in finding out in what ways women who do agree to be in the study might be different from women who don't, so we'd like to ask you a few quick questions.

What is your date of birth? ____/____/____ Refused

What is the highest level of education that you have completed?

1. Less than high school graduate
2. High school graduate
3. Trade or technical school
4. Some college
5. College graduate
6. Some graduate work or graduate degree
7. Refuse
8. Don't know

Have you ever had a mammogram? 1. Yes 2. No 7. Refused 8. Don't know

[CLOSING 2]: Thank you for your time. If you change your mind or have any questions about the project, please call Dr. Lipkus or Jenny Terrenoire at 956-5644. Goodbye.

[IF YES, WILLING TO PARTICIPATE]: We really appreciate your involvement with our project.

In order for us to be able to use the information you give us during the 3 interviews, and also so that we can pay you for your participation in our project, we have to obtain what is known as "informed consent" from you. This would involve reading a short statement to you over the phone describing the project and informing you of your rights as a participant (it only takes about a minute or so). Then if you agree to be part of the study, we will go ahead and conduct the first interview, and we will send you a copy of the form we read to you so that you can have it for your records. **[READ CONSENT FORM AND OBTAIN VERBAL CONSENT.]**

Now, I'd like to ask you some questions concerning how you feel about mammograms, and also about other health-related issues, if that's OK.

[IF YES, ADMINISTER THE QUESTIONNAIRE].

[IF NO]: When would be a good time to call you back?

Is this the best number to call to reach you? **[IF NO, RECORD NUMBER]:**

() _____

I'll make a note to call you then. Thank you very much. I'll talk to you soon.

Questionnaire

Mammography History

First, I would like to know:

1.1 What is your date of birth?

Month ____ Day ____ Year ____

Month: 97=Refused 98=Don't know
Day: 97=Refused 98=Don't know

Now I would like to ask you a few questions about breast cancer screening and mammograms.

1.2a Have you ever had a mammogram?

1=Yes 2=No 7=Refused 8=Don't Know

*If 1.2a=Yes ➔ 1.2b
No, Refuse, Don't Know ➔ 1.4*

1.2b In what month and year did you have your most recent mammogram?

Month ____ Day ____ Year ____
Estimated ____ Estimated X Estimated ____
Seasonal ____ Real ____
Real ____

Month: 97=Refused 98=Don't Know
Day: 97=Refused 98=Don't Know
Year: 97=Refused 98=Don't Know

1.3a Did you have a mammogram before that?

1=Yes 2=No 7=Refuse 8=Don't Know

*If 1.3a= Yes ➔ 1.3b
No, Refuse, Don't know ➔ 1.4*

1.3b In what month and year did you have it?

Month ____ Day ____ Year ____

Estimated ____ Estimated X Estimated ____
Seasonal ____ Real ____
Real ____

Month: 97=Refused 98=Don't Know
Year: 97=Refused 98=Don't Know

Intentions

FOR WOMEN AGE 50 AND OLDER, PLEASE DETERMINE:

If her most recent mammogram was >12 months from the date of this interview, or she has never had a mammogram, ask 1.4a and 1.4b.

1.4a Are you thinking about having a/another mammogram sometime within the next three months?

1=Yes 2=No 7=Refuse 8=Don't Know

*If 1.4a=Yes ➔ 1.4b
No, Refuse, Don't know ➔ 1.9a*

1.4b Are you definitely planning to have a mammogram sometime within the next three months?

1=Yes 2=No 7=Refuse 8=Don't Know

Go to 1.9a

If her most recent mammogram was ≤ 12 months from the date of this interview, please ask 1.5a and 1.5b.

1.5a Are you thinking about having another mammogram about one year after your most recent mammogram?

1=Yes 2=No 7=Refuse 8=Don't Know

*If 1.5a= Yes \rightarrow 1.5b
No, Refuse, Don't know \rightarrow 1.9a*

1.5b Are you definitely planning on having another mammogram about one year after your most recent mammogram?

1=Yes 2=No 7=Refuse 8=Don't Know

Go to 1.9a

[OR: IF AGE 40-49, DETERMINE]:

If her most recent mammogram was > 24 months from the date of this interview, or she has never had a mammogram, ask 1.6a and 1.6b.

1.6a Are you thinking about having a/another mammogram sometime within the next three months?

1=Yes 2=No 7=Refuse 8=Don't Know

*If 1.6a=Yes \rightarrow 1.6b
No, Refuse, Don't know \rightarrow 1.9a*

1.6b Are you definitely planning to have a mammogram sometime within the next three months?

1=Yes 2=No 7=Refuse 8=Don't Know

Go to 1.9a

If her most recent mammogram was ≤ 24 months from the date of this interview, please ask 1.7a and 1.7b.

1.7a Are you thinking about having another mammogram about one to two years after your most recent mammogram?

1=Yes 2=No 7=Refuse 8=Don't Know

*If 1.7a= Yes \Rightarrow 1.7b
No, Refuse, Don't know \Rightarrow 1.9a*

1.7b Are you definitely planning on having another mammogram about one to two years after your most recent mammogram?

1=Yes 2=No 7=Refuse 8=Don't Know

Go to 1.9a

[OR: IF UNDER AGE 40, ASK 1.8]:

1.8 Are you planning to get a mammogram every one to two years once you have turned 40?

1=Yes 2=No 7=Refuse 8=Don't Know

[ASK EVERYONE THE REMAINDER OF THE QUESTIONS]:

1.9a Do you have an appointment for a mammogram?

1=Yes 2=No 7=Refuse 8=Don't Know

*If 1.9a= Yes \Rightarrow 1.9b
No, Refuse, Don't know \Rightarrow 1.10*

1.9b What is the date of your appointment?

Month _____ Day _____ Year _____

Estimated _____ Estimated _____ Estimated _____

Seasonal _____ Estimated _____ Real _____

Real _____

Month: 97=Refused 98=Don't Know

Day 97=Refused 98=Don't Know

Year: 97=Refused 98=Don't Know

1.10 When did you last have a breast exam by a doctor or other health care professional?

1. Within the past year
2. One to two years ago
3. Three or more years ago
4. Never
7. **Refused**
8. **Don't know**

Lifestyle/Health Information

The next few questions are about your health in general.

2.1 How would you describe your health right now?

1. Excellent
2. Very Good
3. Good
4. Fair
5. Poor
7. **Refused**
8. **Don't know**

The next few statements ask for your views about how you take care of your health. Please tell me if you agree or disagree with each statement I read to you. There are no right or wrong answers. Just answer what is right for you.

2.2 When you are sick, you try to cure yourself rather than go to the doctor.

Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.3 If you feel healthy, you do not go to the doctor for a routine check-up.

Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.4 You keep a record so that you know when to schedule your next doctor's appointment.

Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.5 You rely more on home remedies than on doctors.
Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree

7. **Refused** 8. **Don't know**

2.6a What is your current cigarette smoking status? [Read first three choices only.]

1. Never smoked
2. Used to smoke, but quit → **Specify**-How many years ago? _____
3. Smoke now

7=Refuse **8=Don't Know**

*If 2.6a =Smoke now → 2.6b
Never, Used to, Refuse, Don't know → 3.1a*

2.6b On average, how many cigarettes a day do you smoke?

_____ [One pack=20 cigarettes]

7=Refused **8=Don't know**

Family History

3.1 Was your mother ever told by a doctor that she had breast cancer?

1=Yes 2=No 7=Refused 8=Don't Know

3.2a Were any of your sisters ever told by a doctor that they had breast cancer?

1=Yes 2=No 3=Not applicable--No sisters

7=Refused **8=Don't Know**

*If 3.2a= Yes → 3.2b
No, N/A, Refuse, Don't Know → 3.3a*

3.2b How many of your sisters were told that they had breast cancer?

97=Refused 98=Don't know

3.3a Have any of your daughters ever been told by a doctor that they had breast cancer?

1=Yes

2=No

3=Not applicable--No daughters

7=Refuse

8=Don't Know

If 3.3a= Yes ➔ 3.3b

No, N/A, Refuse, Don't Know ➔ 3.4

3.3b How many of your daughters have been told that they have breast cancer?

97=Refuse

98=Don't know

3.4 There are some new blood tests that may be able to tell if you have a greater chance of getting breast cancer because of something that might have been passed down to you through your blood relatives, that is, through your genes. If this test was free, how interested would you be in having it done? [We don't have the test yet but might soon.]

1. Not at all interested
2. Slightly interested
3. Somewhat interested
4. Interested
5. Very interested
7. **Refused**
8. **Don't know**

Decisional Balance

Following are some statements a person might make about mammograms. I'd like to know if you agree or disagree with these statements. Again, there are no right or wrong answers.

4.1 Your family will benefit if you have a mammogram.
Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither agree nor disagree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

4.2 You are more likely to go for mammograms if your doctor tells you it is important for you. Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither agree nor disagree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

4.3 Having mammograms every year or two gives you a feeling of control over your health.
Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither agree nor disagree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

4.4 Having mammograms every year or two gives you peace of mind about your health.
Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

4.5 Women need mammograms even when they have no family history of breast cancer.
Would you say you disagree, agree, or neither disagree nor agree?

- 1. Strongly disagree
- 2. Disagree
- 3. Neither disagree nor agree
- 4. Agree
- 5. Strongly agree
- 7. **Refused**
- 8. **Don't know**

4.6. Mammograms often lead to unnecessary surgery.
Would you say you disagree, agree, or neither disagree nor agree?

- 1. Strongly disagree
- 2. Disagree
- 3. Neither disagree nor agree
- 4. Agree
- 5. Strongly agree
- 7. **Refused**
- 8. **Don't know**

4.7 Having mammograms causes a lot of worry or anxiety about breast cancer.
Would you say you disagree, agree, or neither disagree nor agree?

- 1. Strongly disagree
- 2. Disagree
- 3. Neither disagree nor agree
- 4. Agree
- 5. Strongly agree
- 7. **Refused**
- 8. **Don't know**

4.8 Once you have a couple of mammograms that are normal, you don't need any more for a few years. Would you say you disagree, agree, or neither disagree or agree?

- 1. Strongly disagree
- 2. Disagree
- 3. Neither disagree nor agree
- 4. Agree
- 5. Strongly agree
- 7. **Refused**
- 8. **Don't know**

4.9 The cost of mammograms would cause you to hesitate about getting one.
Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

4.10 It is confusing because there is so much different information about how often women should have mammograms.
Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

4.11 The pain caused by having a mammogram is bad enough to make you put off getting one.
Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

4.12 You are torn about whether you should or should not get a mammogram within the next year or two. Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

4.13 How effective do you think mammograms are in finding breast cancer early?

1. Not at all effective
2. Somewhat effective
3. Effective
4. Very effective
7. **Refused**
8. **Don't know**

4.14 Overall, your attitude towards having a mammogram is **[Read choices 1-5 only.]**

1. Not at all favorable
2. Slightly favorable
3. Somewhat favorable
4. Very favorable
5. Extremely favorable
7. **Refused**
8. **Don't know**

Knowledge of Breast Cancer

I will now mention several items that may or may not be related to getting breast cancer. Please let me know whether or not **you** think each item is related to getting breast cancer. [Do **not** mention age ranges below (in brackets) unless asked to clarify.]

5.1	Being older [age 50 and older]	1=Yes	2=No	7=Refused	8=Don't know
5.2	Having a family history	1=Yes	2=No	7=Refused	8=Don't know
5.3	Having lots of stress	1=Yes	2=No	7=Refused	8=Don't know
5.4	Having a breast injury (like a bruise)	1=Yes	2=No	7=Refused	8=Don't know
5.5	Being older when you have your first child [over age 30]	1=Yes	2=No	7=Refused	8=Don't know
5.6	Never having had children	1=Yes	2=No	7=Refused	8=Don't know
5.7	Late age of menopause [over age 55]	1=Yes	2=No	7=Refused	8=Don't know
5.8	Early age of starting periods [under age 12]	1=Yes	2=No	7=Refused	8=Don't know
5.9	Never having breastfed	1=Yes	2=No	7=Refused	8=Don't know

5.10 How often should a woman your age get a mammogram? [DO NOT READ CHOICES]

1. Every year
2. Every 1-2 years
3. Every 3 years or more
4. Only if there are symptoms/pain
5. Only when the doctor recommends it
6. Other (specify): _____
7. Refuse
8. Don't know

Risk Perceptions

The next few questions are about your thoughts about getting breast cancer.

6.1 Compared to other African-American women your age, what do you think is your chance of getting breast cancer in your lifetime?

Would you say ... [Read choices 1-5 only.]

1. Much lower
2. Somewhat lower
3. About the same
4. Somewhat higher
5. Much higher
7. **Refused**
8. **Don't know**

6.2 What do you think is your chance of getting breast cancer in your lifetime?

Would you say ... [Read choices 1-5 only.]

1. Very unlikely
2. Unlikely
3. Moderate chance
4. Likely
5. Very likely
7. **Refused**
8. **Don't know**

If Refuse, Don't Know ➔ Go to 6.4

6.3 In the previous question, you mentioned that your risk of getting breast cancer was [See question 6.2.] _____. What things did you think about that led you to choose that answer? [DO NOT READ CHOICES; MAY CIRCLE MORE THAN 1]

1. Age (younger)
2. Age (older)
3. Family history (positive)
4. Family history (negative)
5. Exercise (regular)
6. Exercise (little or none)
7. Diet (good)
8. Diet (bad)
9. Faith in God
10. Breast injury
11. Don't have symptoms (pain, lumps, etc.)
12. Have symptoms
13. I get regular mammograms
14. I get regular breast exams (CBE)
15. Based on what my doctor told me
16. Because I breastfed
96. Other (specify): _____
97. Refuse
98. Don't know

6.4 How concerned are you about getting breast cancer?
Would you say ...[Read choices 1-5 only.]

1. Not at all concerned
2. Slightly concerned
3. Somewhat concerned
4. Concerned
5. Very concerned
7. Refused
8. Don't know

Psychological Well-being

The following questions are about how you have been feeling within the last month. For each question, please give the one answer that comes CLOSEST to the way you have been feeling within the last month. I will repeat the choices if you would like me to.

Within the last month, how much of the time were you ...

7.1 A very nervous person? Would you say ... [Read choices 1-5 only.]

1. None of the time
2. A little bit of the time
3. About half the time
4. Most of the time
5. All of the time
7. **Refused**
8. **Don't know**

Within the last month, how much of the time were you...

7.2 So down in the dumps that nothing could cheer you up?
Would you say ... [Read choices 1-5 only.]

1. None of the time
2. A little bit of the time
3. About half the time
4. Most of the time
5. All of the time
7. **Refused**
8. **Don't know**

Within the last month, how much of the time were you ...

7.3 Calm and peaceful?
Would you say ... [Read choices 1-5 only.]

1. None of the time
2. A little bit of the time
3. About half the time
4. Most of the time
5. All of the time
7. **Refused**
8. **Don't know**

Within the last month, how much of the time were you...

7.4 Downhearted and blue?

Would you say ... [Read choices 1-5 only.]

1. None of the time
2. A little bit of the time
3. About half the time
4. Most of the time
5. All of the time
7. **Refused**
8. **Don't know**

Within the last month, how much of the time were you...

7.5 A happy person?

Would you say ... [Read choices 1-5 only.]

1. None of the time
2. A little bit of the time
3. About half the time
4. Most of the time
5. All of the time
7. **Refused**
8. **Don't know**

Just World

These next questions are about your own personal outlook on life and the world in general. Please tell me whether you agree or disagree with each question.

8.1 You feel you get what you are entitled to have in life.

Would you say you agree, disagree, or neither agree nor disagree?

1=Strongly agree
2=Agree
3=Neither agree or disagree
4=Disagree
5=Strongly disagree
7=Refuse
8=Don't Know

8.2 You feel that your efforts are noticed and rewarded.
Would you say you agree, disagree, or neither agree nor disagree?

1=Strongly agree
2=Agree
3=Neither agree or disagree
4=Disagree
5=Strongly disagree
7=Refuse 8=Don't Know

8.3 You feel that people treat you fairly.
Would you say you agree, disagree, or neither agree nor disagree?

1=Strongly agree
2=Agree
3=Neither agree or disagree
4=Disagree
5=Strongly disagree
7=Refuse 8=Don't Know

8.4 You feel that when you meet with misfortune, you have brought it upon yourself.
Would you say you agree, disagree, or neither agree nor disagree?

1=Strongly agree
2=Agree
3=Neither agree or disagree
4=Disagree
5=Strongly disagree
7=Refuse 8=Don't Know

8.5 You feel you get what you deserve in life.
Would you say you agree, disagree, or neither agree nor disagree?

1=Strongly agree
2=Agree
3=Neither agree or disagree
4=Disagree
5=Strongly disagree
7=Refuse 8=Don't Know

8.6 You feel that people treat you with the respect that you deserve.
Would you say you agree, disagree, or neither agree nor disagree?

1=Strongly agree
2=Agree
3=Neither agree or disagree
4=Disagree
5=Strongly disagree
7=Refuse 8=Don't Know

8.7 You feel the world treats you fairly.
Would you say you agree, disagree, or neither agree nor disagree?

1=Strongly agree
2=Agree
3=Neither agree or disagree
4=Disagree
5=Strongly disagree
7=Refuse 8=Don't Know

Demographics

Now I would like to take a moment to update our records.

9.1 What is the highest level of education that you have completed? **[NOTE: READ CHOICES ONLY IF ASKED]**

1. Less than high school graduate
2. High school graduate
3. Trade or technical school
4. Some college
5. College graduate
6. Some graduate work or graduate degree
7. **Refuse**
8. **Don't know**

9.2 What is your marital status? **[NOTE: READ CHOICES 1-6 ONLY]**

1. Married
2. Living as married
3. Widowed
4. Divorced
5. Separated
6. Single, never married
7. Other (specify): _____

97. Refused

9.3 Which of the following best describes your present working status? [NOTE: READ CHOICES 1-5 ONLY]

1. Working part-time
2. Working full-time
3. Full-time homemaker
4. Retired
5. Unemployed
6. Other (specify): _____
[Can include disabled, volunteer worker, student, taking care of sick relative, etc.]

97. Refused

98. Don't know

9.4 Do you have health insurance coverage? [NOTE: IF NO, CIRCLE #6 (NONE); IF YES, ASK "WHAT KIND OF INSURANCE DO YOU HAVE?", AND READ CHOICES 1-5]

1. Medicaid
2. Medicare
3. Commercial insurance, such as Blue Cross/Blue Shield
4. Health maintenance organization (HMO), e.g. Kaiser
5. Managed care, e.g. Sanus
6. None
7. Other (specify): _____

97. Refused

98. Don't know

9.5a Do you still live at (*read current address*)?
1=Yes 2=No 7=Refuse 8=Don't know

If 9.5a= Yes ➔ 9.6
No, Refused, Don't know ➔ 9.5b

9.5b What is your current address?

Street address/Apt #/PO Box _____
City _____ State _____ Zip _____

9.6 We will be calling you again in about 3-4 months (before then we will be sending information for you to read on mammography). What is the best number to call to reach you, and what would be the best days/times to call?

() - _____ Best day(s) to call _____ Best time(s) _____

9.7 Can you give me the name and phone number of another person we could contact who would know how to reach you, in case you move or change your phone number?

First Name _____ Last Name _____

Telephone number () -

9.8 Finally, we would like to know if you would be interested in completing a questionnaire about your personality. The questionnaire would be mailed to your home with a self-addressed return stamped envelope. It will take about 30 minutes to one hour to complete, and you would be paid \$25.00.

[SAY ONLY IF ASKED ABOUT WHAT THE QUESTIONNAIRE IS FOR: "The reason we want to ask you questions about your personality is to gain a better understanding of whether certain personality characteristics affect how people interpret information about mammography and breast cancer screening."] Completing this questionnaire is entirely voluntary and will not affect your participation in this study. Furthermore, as with all information you provide, it will be kept strictly confidential. Would you like us to mail you this personality questionnaire to your home?

1. Yes 2. No 3. Undecided--call back

Thank you very much for your time and help. As I mentioned before, we will be sending you a brochure about breast cancer and mammography in about 3 months. When you get this important information, please read it carefully. If you have any questions, please call Jenny Terrenoire or Dr. Lipkus at 956-5644. Thanks again.

10.1 Comments:

Total Interview Time: ____ minutes

Appendix B
Message Framing (Gain/Loss/Control)
Psychoeducational Brochures

WHAT YOU GAIN BY HAVING REGULAR MAMMOGRAMS

- By having regular mammograms, you are doing your best to find breast cancer early.
- By having regular mammograms you gain peace of mind, knowing that you are doing your best to keep your breasts healthy.
- If breast cancer is found early, it is less likely to be fatal.
- By finding breast cancer early, you have more treatment options and may need less extreme medical procedures (for example, not having to remove large parts or all of the breast).
- Having regular mammograms means that you are taking charge of your own health!
- If you get a mammogram, you are using the best method to find out if your breasts are healthy.

Say Yes to Life



To find out more about breast cancer and mammograms, call the Cancer Information Service

1-800-422-6237
(1-800-4-CANCER)

Get Regular Mammograms

By taking care of ourselves we are taking care of each other.

Together, we can fight breast cancer!

Duke Comprehensive Cancer Center

Supported by US Department of Defense grant #DAMD17-96-1-6148.



As one African-American woman said, *“Two of my very dear friends have been diagnosed with breast cancer. Both of them found it early with a mammogram. And both of them are still with me today. Getting regular mammograms has become a must for me!”*

FACTS ABOUT BREAST CANCER

- About 1 out of 11 African-American women will get breast cancer in her lifetime.
- Breast cancer is the leading cause of cancer death for African-American women.

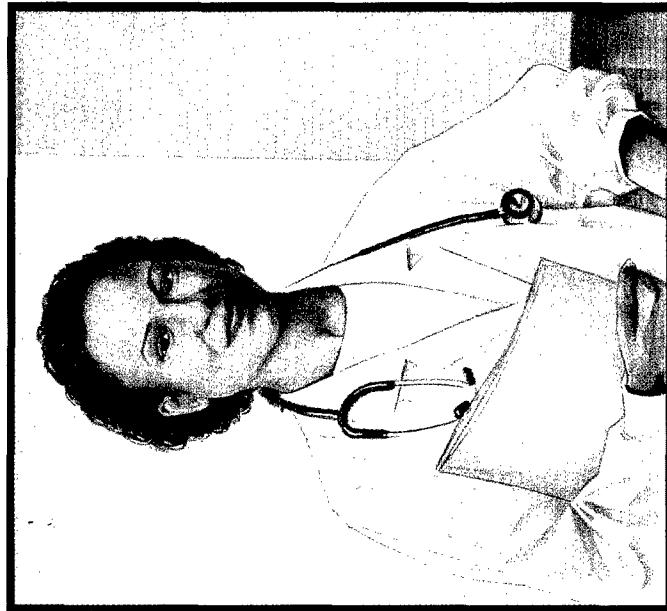
FACTORS THAT MAY INCREASE THE RISK OF BREAST CANCER

Health experts have found several factors related to breast cancer.

- Age. The older a woman is, the greater her chances are of getting breast cancer.
- Having someone in your family who has had breast cancer. However, most women who get breast cancer do not have a family history.
- Atypical hyperplasia, a special kind of breast problem that is found on a breast biopsy (a procedure that takes out and examines breast tissue).
- Having no children, or having your first child after age 30.

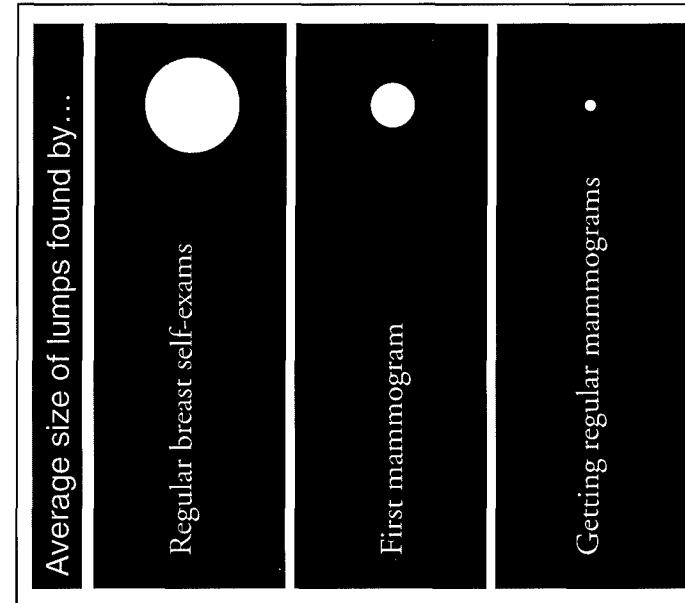
Breast cancer is **not** caused by:

- High levels of stress.
- Bruises or injuries to a breast.



WHAT MAMMOGRAMS CAN DO

- As the picture below shows, mammograms are the best way of finding breast cancer early. Mammograms can find breast cancer up to two years before it can be seen or felt.



WHAT YOU CAN DO TO TAKE CARE OF YOUR BREASTS

The National Cancer Institute says:

- ✓ Get a mammogram, which is a simple x-ray exam of the breast. You should get a mammogram:
 - Every year if you are 50 or older.
 - If you are under 50, talk to your doctor about what would be best for you.
- ✓ Check your breasts for lumps or changes every month.
- ✓ Get a breast exam by a health care provider every year.

**The best weapon
to fight breast cancer
is to find it early!**

Appendix C
**Three-month Follow-up Telephone Interview
Questionnaire**

INTRODUCTION TO 3 MO. FOLLOW-UP QUESTIONNAIRE

- >Hello, my name is _____, and I'm calling for Dr. Isaac Lipkus at the Comprehensive Cancer Center at Duke Medical Center. About 3-4 months ago you joined our project about African-American women and mammograms, and at that time we interviewed you over the phone. About a week or so ago we sent you a brochure with important information about breast cancer and mammograms. Did you receive the brochure?

[CIRCLE ONE]: 1. Yes 2. No 3. Not sure/Don't remember

[IF NO, DID NOT RECEIVE BROCHURE]: Let me make sure we have your correct mailing address:

[RECORD MAILING ADDRESS] _____

We'll send you another brochure, and then call you back about a week after that to get your thoughts about the brochure. Thanks very much, I'll talk to you soon. Goodbye.

[IF YES, DID RECEIVE THE BROCHURE]: If you have a minute I'd like to ask you some questions about your thoughts on the brochure, and also a few health-related questions (similar to the ones we asked you during our first phone conversation about 3-4 months ago). It shouldn't take more than 15-20 minutes at the most.

[IF WRITTEN OR VERBAL CONSENT HAS NOT BEEN OBTAINED YET, SAY THE FOLLOWING:] But first, in order for us to be able to use the information you give us during the interviews, and also so that we can pay you for your participation in our project, we have to obtain what is known as "informed consent" from you. This would involve reading a short statement to you over the phone describing the project (it only takes about a minute or so). Then we will send you a copy of the form we read to you so that you can have it for your records.

[READ CONSENT FORM AND OBTAIN VERBAL CONSENT.]

Now, I'd like to go ahead and start the interview, if that's OK.

[IF YES, ADMINISTER THE QUESTIONNAIRE].

[IF NO]: When would be a good time to call you back?

Is this the best number to call to reach you? **[IF NO, RECORD NUMBER]:**

() _____ - _____

I'll make a note to call you then. Thank you very much. I'll talk to you soon.

Follow-up Questionnaire

Mammography History

First, I would like to ask you a few questions about breast cancer screening and mammograms.

1.1a Have you had a mammogram since we first talked to you on the phone about 3-4 months ago?

1=Yes 2=No 7=Refused 8=Don't know

*If 1.1a= Yes ➔ 1.1b
No, Refuse, Don't know ➔ 1.2*

1.1b In what month and year did you have it?

Month _____ Day _____ Year _____
Estimated _____ Estimated X Estimated _____
Seasonal _____ Real _____
Real _____

Month: 97=Refused 98=Don't Know
Day: 97=Refused 98=Don't Know
Year: 97=Refused 98=Don't Know

Intentions

[IF UNDER AGE 40, SKIP TO 1.7]

IF AGE 40 AND OVER, ASK:

1.2 Are you planning to talk to your doctor sometime during the next 4 months about mammograms?

1=Yes 2=No 7=Refuse 8=Don't Know

FOR WOMEN AGE 50 AND OLDER, PLEASE DETERMINE:

If her most recent mammogram was >12 months from the date of this interview, or she has never had a mammogram, ask 1.3a and 1.3b.

1.3a Are you thinking about having a/another mammogram sometime within the next four months?

1=Yes 2=No 7=Refuse 8=Don't Know

*If 1.3a=Yes ➔ 1.3b
No, Refuse, Don't know ➔ 1.9a*

1.3b Are you definitely planning to have a mammogram sometime within the next four months?

1=Yes 2=No 7=Refuse 8=Don't Know

Go to 1.9a

If her most recent mammogram was ≤12 months from the date of this interview, please ask 1.4a and 1.4b.

1.4a Are you thinking about having another mammogram about one year after your most recent mammogram?

1=Yes 2=No 7=Refuse 8=Don't Know

*If 1.4a= Yes ➔ 1.4b
No, Refuse, Don't know ➔ 1.9a*

1.4b Are you definitely planning on having another mammogram about one year after your most recent mammogram?

1=Yes 2=No 7=Refuse 8=Don't Know

Go to 1.9a

[OR: IF AGE 40-49, DETERMINE]:

If her most recent mammogram was >24 months from the date of this interview, or she has never had a mammogram, ask 1.5a and 1.5b.

1.5a Are you thinking about having a/another mammogram sometime within the next four months?

1=Yes 2=No 7=Refuse 8=Don't Know

*If 1.5a=Yes ➔ 1.5b
No, Refuse, Don't know ➔ 1.9a*

1.5b Are you definitely planning to have a mammogram sometime within the next four months?

1=Yes 2=No 7=Refuse 8=Don't Know

Go to 1.9a

If her most recent mammogram was ≤24 months from the date of this interview, please ask 1.6a and 1.6b.

1.6a Are you thinking about having another mammogram about one to two years after your most recent mammogram?

1=Yes 2=No 7=Refuse 8=Don't Know

*If 1.6a= Yes ➔ 1.6b
No, Refuse, Don't know ➔ 1.9a*

1.6b Are you definitely planning on having another mammogram about one to two years after your most recent mammogram?

1=Yes 2=No 7=Refuse 8=Don't Know

Go to 1.9a

[OR: IF UNDER AGE 40, ASK 1.7 AND 1.8]:

1.7 Are you planning to talk to your doctor about mammograms when you reach age 40?

1=Yes 2=No 7=Refuse 8=Don't Know

1.8 Are you planning to get a mammogram every one to two years once you have turned 40?

1=Yes 2=No 3=Only if doctor recommends 7=Refuse 8=Don't Know

[ASK EVERYONE THE REMAINDER OF THE QUESTIONS]:

1.9a Do you have an appointment for a mammogram?

1=Yes 2=No 7=Refuse 8=Don't Know

If 1.9a= Yes ➔ 1.9b

No, Refuse, Don't know ➔ 2.1

1.9b What is the date of your appointment?

Month _____ Day _____ Year _____

Estimated _____ Estimated _____ Estimated _____

Seasonal _____ Real _____ Real _____

Real _____

Month: 97=Refused 98=Don't Know

Day 97=Refused 98=Don't Know

Year: 97=Refused 98=Don't Know

Decisional Balance

Following are some statements a person might make about mammograms. I'd like to know if you agree or disagree with these statements. There are no right or wrong answers, just answer

what is right for you.

2.1 Your family will benefit if you have a mammogram.

Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither agree nor disagree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.2 You are more likely to go for mammograms if your doctor tells you it is important for you. Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither agree nor disagree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.3 Having mammograms every year or two gives you a feeling of control over your health. Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither agree nor disagree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.4 Having mammograms every year or two gives you peace of mind about your health. Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.5 Women need mammograms even when they have no family history of breast cancer. Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.6. Mammograms often lead to unnecessary surgery.

Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.7 Having mammograms causes a lot of worry or anxiety about breast cancer. Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.8 Once you have a couple of mammograms that are normal, you don't need any more for a few years. Would you say you disagree, agree, or neither disagree or agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.9 The cost of mammograms would cause you to hesitate about getting one. Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.10 It is confusing because there is so much different information about how often women should have mammograms.
Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.11 The pain caused by having a mammogram is bad enough to make you put off getting one. Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.12 You are torn about whether you should or should not get a mammogram within the next year or two. Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.13 How effective do you think mammograms are in finding breast cancer early?

1. Not at all effective
2. Somewhat effective
3. Effective
4. Very effective

- 7. **Refused**
- 8. **Don't know**

2.14 How worried are you that if you had a mammogram, it might find cancer?

- 1. Not at all worried
- 2. Slightly worried
- 3. Worried
- 4. Very worried
- 7. **Refused**
- 8. **Don't know**

2.15 I'm going to read 2 statements to you about why you might have a mammogram; I'd like to know which statement you agree with **most**:

- 1. You would have a mammogram in order to find out if you have breast cancer.
- 2. You would have a mammogram in order to gain peace of mind in finding out that you do not have breast cancer.
- 7. **Refused**
- 8. **Don't know**

2.16 Overall, your attitude towards having a mammogram is **[Read choices 1-5 only.]**

- 1. Not at all favorable
- 2. Slightly favorable
- 3. Somewhat favorable
- 4. Very favorable
- 5. Extremely favorable
- 7. **Refused**
- 8. **Don't know**

Knowledge of Breast Cancer

I will now mention several items that may or may not be related to getting breast cancer. Please let me know whether or not **you** think each item is related to getting breast cancer. **[Do not mention age ranges below (in brackets) unless asked to clarify.]**

3.1 Being older [age 50 and older]	1=Yes	2=No	7=Refused	8=Don't know
3.2 Having a family history	1=Yes	2=No	7=Refused	8=Don't know
3.3 Having lots of stress	1=Yes	2=No	7=Refused	8=Don't know
3.4 Having a breast injury (like a bruise)	1=Yes	2=No	7=Refused	8=Don't know
3.5 Being older when you have your first child [over age 30]	1=Yes	2=No	7=Refused	8=Don't know
3.6 Never having had children	1=Yes	2=No	7=Refused	8=Don't know
3.7 Having atypical hyperplasia (a kind of breast problem that can be found with a breast biopsy)	1=Yes	2=No	7=Refused	8=Don't know

3.8 How often should a woman your age get a mammogram? [DO NOT READ CHOICES]

1. Every year
2. Every 1-2 years
3. Every 3 years or more
4. Only if there are symptoms/pain
5. Only when the doctor recommends it
6. Other (specify): _____
7. Refuse
8. Don't know

Risk Perceptions

The next few questions are about your thoughts about getting breast cancer.

4.1 Compared to other African-American women your age, what do you think is your chance of getting breast cancer in your lifetime?
Would you say ... [Read choices 1-5 only.]

1. Much lower
2. Somewhat lower
3. About the same
4. Somewhat higher
5. Much higher
7. **Refused**
8. **Don't know**

4.2 What do you think is your chance of getting breast cancer in your lifetime?
Would you say ... **[Read choices 1-5 only.]**

1. Very unlikely
2. Unlikely
3. Moderate chance
4. Likely
5. Very likely
7. **Refused**
8. **Don't know**

If Refuse, Don't Know ➔ Go to 4.4

4.3 In the previous question, you mentioned that your risk of getting breast cancer was **[See question 4.2.]** _____ . What things did you think about that led you to choose that answer? **[DO NOT READ CHOICES; MAY CIRCLE MORE THAN 1]**

1. Age (younger)
2. Age (older)
3. Family history (positive)
4. Family history (negative)
5. Exercise (regular)
6. Exercise (little or none)
7. Diet (good)

8. Diet (bad)
9. Faith in God
10. Breast injury
11. Don't have symptoms (pain, lumps, etc.)
12. Have symptoms
13. I get regular mammograms
14. I get regular breast exams (CBE)
15. Based on what my doctor told me
16. Because I breastfed
17. Not applicable [ANSWERED REFUSE OR DON'T KNOW TO PREV. Q]
96. Other (specify): _____
97. Refuse
98. Don't know

4.4 How concerned are you about getting breast cancer?
Would you say ... [Read choices 1-5 only.]

1. Not at all concerned
2. Slightly concerned
3. Somewhat concerned
4. Concerned
5. Very concerned
7. Refused
8. Don't know

Psychological Well-being

The following questions are about how you have been feeling within the last month. For each question, please give the one answer that comes CLOSEST to the way you have been feeling within the last month. I will repeat the choices if you would like me to.

Within the last month, how much of the time were you ...

5.1 A very nervous person? Would you say ... [Read choices 1-5 only.]

1. None of the time
2. A little bit of the time
3. About half the time

- 4. Most of the time
- 5. All of the time
- 7. **Refused**
- 8. **Don't know**

Within the last month, how much of the time were you...

5.2 So down in the dumps that nothing could cheer you up?
Would you say ... **[Read choices 1-5 only.]**

- 1. None of the time
- 2. A little bit of the time
- 3. About half the time
- 4. Most of the time
- 5. All of the time
- 7. **Refused**
- 8. **Don't know**

Within the last month, how much of the time were you ...

5.3 Calm and peaceful?
Would you say ... **[Read choices 1-5 only.]**

- 1. None of the time
- 2. A little bit of the time
- 3. About half the time
- 4. Most of the time
- 5. All of the time
- 7. **Refused**
- 8. **Don't know**

Within the last month, how much of the time were you...

5.4 Downhearted and blue?
Would you say ... **[Read choices 1-5 only.]**

- 1. None of the time
- 2. A little bit of the time
- 3. About half the time
- 4. Most of the time
- 5. All of the time
- 7. **Refused**
- 8. **Don't know**

Within the last month, how much of the time were you...

5.5 A happy person?

Would you say ... [Read choices 1-5 only.]

1. None of the time
2. A little bit of the time
3. About half the time
4. Most of the time
5. All of the time
7. **Refused**
8. **Don't know**

Brochure Questions

Now I would like to ask you some questions about the brochure we sent you about mammograms and breast cancer screening.

6.1 How much of the brochure did you read?

1. None of it [SKIP TO 7.1a]
2. Some of it
3. Most of it
4. All of it
7. **Refused**
8. **Don't know**

6.2 To what extent did the brochure emphasize what you have to **gain** by having regular mammograms?

1. Not at all
2. Slightly
3. Somewhat
4. A lot
7. **Refused**
8. **Don't know**

6.3 To what extent did the brochure emphasize what you have to **lose** by not having regular mammograms?

1. Not at all

- 2. Slightly
- 3. Somewhat
- 4. A lot
- 7. **Refused**
- 8. **Don't know**

Now I will be mentioning different ways that the messages in the brochure may have made you feel.

6.4 Did the brochure make you feel:

- 1. Not at all scared
- 2. Slightly scared
- 3. Somewhat scared
- 4. Scared
- 5. Very scared
- 7. **Refused**
- 8. **Don't know**

6.5 Did the brochure make you feel:

- 1. Not at all reassured
- 2. Slightly reassured
- 3. Somewhat reassured
- 4. Reassured
- 5. Very reassured
- 7. **Refused**
- 8. **Don't know**

6.6 Did the brochure make you feel:

- 1. Not at all nervous
- 2. Slightly nervous
- 3. Somewhat nervous

- 4. Nervous
- 5. Very nervous
- 7. **Refused**
- 8. **Don't know**

6.7 Did the brochure make you feel:

- 1. Not at all comforted
- 2. Slightly comforted
- 3. Somewhat comforted
- 4. Comforted
- 5. Very comforted
- 7. **Refused**
- 8. **Don't know**

6.8 Did the brochure make you feel:

- 1. Not at all concerned
- 2. Slightly concerned
- 3. Somewhat concerned
- 4. Concerned
- 5. Very concerned
- 7. **Refused**
- 8. **Don't know**

6.9 Did the brochure make you feel:

- 1. Not at all relieved
- 2. Slightly relieved
- 3. Somewhat relieved
- 4. Relieved
- 5. Very relieved
- 7. **Refused**
- 8. **Don't know**

6.10 Now I'm going to read 3 statements to you about how the brochure might have affected your plans for getting regular mammograms, and I'd like you to tell me which statement you agree with **most**:

- 1. The brochure made you feel that you were less likely to get regular mammograms
- 2. The brochure made you feel that you were more likely to get regular

mammograms

- 3. The brochure did not change your plans about getting regular mammograms
- 7. **Refused**
- 8. **Don't know**

6.11 The next 3 statements are about how the brochure might have affected how you see your chances of getting breast cancer someday; again, I'd like to know which statement you agree with **most**:

- 1. The brochure made you feel less likely to get breast cancer
- 2. The brochure made you feel more likely to get breast cancer
- 3. The brochure did not change your feelings about your chances of getting breast cancer
- 7. **Refused**
- 8. **Don't know**

6.12 How interested were you in the brochure?

- 1. Not at all interested
- 2. Slightly interested
- 3. Somewhat interested
- 4. Interested
- 5. Very interested
- 7. **Refused**
- 8. **Don't know**

6.13 Was the information in the brochure personally useful to you?
Would you say ...

- 1. Not at all useful
- 2. Slightly useful
- 3. Somewhat useful
- 4. Useful
- 5. Very useful
- 7. **Refused**
- 8. **Don't know**

Demographics

I just have a few more questions to ask you, to make sure our records are up to date.

7.1a Do you still live at (*read current address*)?

1=Yes

2=No

7=Refuse

8=Don't know

If 7.1a= Yes → 7.2

No, Refused, Don't know → 7.1b

7.1b What is your current address?

Street address/Apt #/PO Box _____
City _____ State _____ Zip _____

7.2 We will be calling you one more time in about 4 months. What is the best number to call to reach you, and what would be the best days/times to call?

(____) - _____ Best day(s) to call _____ Best time(s) _____

[ASK 7.4 ONLY IF WOMAN SAID AT BASELINE INTERVIEW THAT SHE WANTED PERSONALITY QUESTIONNAIRE SENT TO HER HOME BUT DID NOT RETURN IT]:

7.4 Finally, we would like to know if you are still interested in completing a questionnaire about your personality. If you are and don't still have the one we sent you before, we'll mail the questionnaire out to you again with a self-addressed, stamped return envelope. It will take about 30 minutes to complete, and you will be paid \$25.00. We will send you a check for that amount as soon as we receive the completed questionnaire back from you in the mail.

[SAY ONLY IF ASKED ABOUT WHAT THE QUESTIONNAIRE IS FOR: "The reason we want to ask you questions about your personality is to gain a better understanding of whether certain personality characteristics affect how people view information about mammography and breast cancer screening."]

Completing this questionnaire is entirely voluntary and will not affect your participation in our project. Furthermore, as with all information you provide, it will be kept strictly confidential. Would you like us to mail you this personality questionnaire to your home again?

1. Yes

2. No

3. Undecided--call back

Thank you very much for your time and help. As I mentioned before, we will be calling you one last time in about 4 months to ask you a few more questions related to mammograms and breast cancer, which will be similar to questions we've already asked you. If you have any questions in the meantime, please call Jenny Terrenoire or Dr. Lipkus at 956-5644. Thanks again for your time.

8.1 Comments:

Total Interview Time: ____ minutes

Appendix D
Final Telephone Interview Questionnaire

Final Questionnaire

Mammography History

First, I would like to ask you a few questions about breast cancer screening and mammograms.

1.1a Have you ever had a mammogram?

1=Yes

2=No

7=Refuse

8=Don't know

If 1.1a= Yes = 1.1b

No, Refuse, Don't know = 1.2

1.1b Have you had a mammogram since we last talked to you on the phone about 4-5 months ago?

1=Yes

2=No

7=Refused

8=Don't know

1.1c In what month and year did you have your most recent mammogram?

Month____ Day____ Year____

Estimated____ Estimated X Estimated____

Seasonal ____ Real ____

Real ____

Month: 97=Refused 98=Don't Know

Day: 97=Refused 98=Don't Know

Year: 97=Refused 98=Don't Know

1.1d Have you ever had an abnormal mammogram, that is, one that required more tests?

1. Yes

2. No

7. Refuse

8. Don't know

Intentions

[IF UNDER AGE 40, SKIP TO 1.7]

IF AGE 40 AND OVER, ASK:

1.2 Are you planning to talk to your doctor sometime during the next 4 months about mammograms?

1=Yes

2=No

7=Refuse

8=Don't Know

FOR WOMEN AGE 50 AND OLDER, PLEASE DETERMINE:

If her most recent mammogram was >12 months from the date of this interview, or she has never had a mammogram, ask 1.3a and 1.3b.

1.3a Are you thinking about having a/another mammogram sometime within the next four months?

1=Yes

2=No

7=Refuse

8=Don't Know

If 1.3a=Yes = 1.3b

No, Refuse, Don't know = 1.8

1.3b Are you definitely planning to have a mammogram sometime within the next four months?

1=Yes

2=No

7=Refuse

8=Don't Know

Go to 1.8

If her most recent mammogram was #12 months from the date of this interview, please ask 1.4a and 1.4b.

1.4a Are you thinking about having another mammogram about one year after your most recent mammogram?

1=Yes

2=No

7=Refuse

8=Don't Know

If 1.4a= Yes = 1.4b

No, Refuse, Don't know = 1.8

1.4b *Are you definitely planning on having another mammogram about one year after your most recent mammogram?*

1=Yes

2=No

7=Refuse

8=Don't Know

Go to 1.8

[OR: IF AGE 40-49, DETERMINE]:

If her most recent mammogram was >24 months from the date of this interview, or she has never had a mammogram, ask 1.5a and 1.5b.

1.5a *Are you thinking about having a/another mammogram sometime within the next four months?*

1=Yes

2=No

7=Refuse

8=Don't Know

If 1.5a=Yes ≡ 1.5b

No, Refuse, Don't know ≡ 1.8

1.5b *Are you definitely planning to have a mammogram sometime within the next four months?*

1=Yes

2=No

7=Refuse

8=Don't Know

Go to 1.8

If her most recent mammogram was #24 months from the date of this interview, please ask 1.6a and 1.6b.

1.6a *Are you thinking about having another mammogram about one to two years after your most recent mammogram?*

1=Yes

2=No

7=Refuse

8=Don't Know

If 1.6a= Yes ≡ 1.6b

No, Refuse, Don't know ≡ 1.8

1.6b *Are you definitely planning on having another mammogram about one to two years after your most recent mammogram?*

1=Yes

2=No

7=Refuse

8=Don't Know

Go to 1.8

[OR: IF UNDER AGE 40, ASK 1.7]:

1.7 Are you planning to get a mammogram every one to two years once you have turned 40?

1=Yes 2=No 3=Only if doctor recommends 7=Refuse 8=Don't Know

[ASK EVERYONE THE REMAINDER OF THE QUESTIONS]:

1.8 Do you have an appointment for a mammogram?

1=Yes 2=No 7=Refuse 8=Don't Know

Decisional Balance

Following are some statements a person might make about mammograms. I'd like to know if you agree or disagree with these statements. There are no right or wrong answers, just answer what is right for you.

2.1 Your family will benefit if you have a mammogram.

Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither agree nor disagree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.2 You are more likely to go for mammograms if your doctor tells you it is important for you. Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither agree nor disagree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.3 Having mammograms every year or two gives you a feeling of control over your health. Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither agree nor disagree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.4 Having mammograms every year or two gives you peace of mind about your health. Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.5 Women need mammograms even when they have no family history of breast cancer. Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.6. Mammograms often lead to unnecessary surgery.
Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.7 Having mammograms causes a lot of worry or anxiety about breast cancer.
Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.8 Once you have a couple of mammograms that are normal, you dont need any more for a few years. Would you say you disagree, agree, or neither disagree or agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.9 The cost of mammograms would cause you to hesitate about getting one.
Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.10 It is confusing because there is so much different information about how often women should have mammograms.
Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.11 The pain caused by having a mammogram is bad enough to make you put off getting one.
Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

[IF UNDER 40, ASK THE NEXT 3 QUESTIONS]:

2.12 You are torn about whether you should or should not get a mammogram every one to two years once you have turned 40. Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.13 You have mixed feelings about whether you should or should not get a mammogram every one to two years once you have turned 40. Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.14 You have conflicting thoughts about whether you should or should not get a mammogram every one to two years once you have turned 40. Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

[IF AGE 40-49, ASK THE NEXT 3 QUESTIONS]:

2.15 You are torn about whether you should or should not get a mammogram every one to two years. Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.16 You have mixed feelings about whether you should or should not get a mammogram every one to two years. Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refuse**
8. **Don't know**

2.17 You have conflicting thoughts about whether you should or should not get a mammogram every one to two years. Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

[IF AGE 50 OR OLDER, ASK THE NEXT 3 QUESTIONS]:

2.18 You are torn about whether you should or should not get a mammogram every year. Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.19 You have mixed feelings about whether you should or should not get a mammogram every year. Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refuse**
8. **Don't know**

2.20 You have conflicting thoughts about whether you should or should not get a mammogram every year. Would you say you disagree, agree, or neither disagree nor agree?

1. Strongly disagree
2. Disagree
3. Neither disagree nor agree
4. Agree
5. Strongly agree
7. **Refused**
8. **Don't know**

2.21 Overall, your attitude towards having a mammogram is [Read choices 1-5 only.]

1. Not at all favorable
2. Slightly favorable
3. Somewhat favorable
4. Very favorable
5. Extremely favorable
7. **Refused**
8. **Don't know**

Genetic Testing

The following questions are about breast cancer and genetic testing. Genes contain the biological information that is passed to you from your blood relatives. For example, genes affect the color of your hair and eyes, your height and weight and many other things about you.

3.1 Do you understand what genes are?

1. Yes
2. No
7. **Refuse**
8. **Don't know**

[IF YES, SKIP TO NEXT PAGE.]

[IF NO, SAY THE FOLLOWING:] Much of who you are as a person, such as how you look, comes to you from your blood relatives. Your body stores this inherited information in genes, which contain messages from your relatives that help define who you are.

Medical researchers are finding genes that seem to affect a woman's chances of getting breast cancer. I want to know whether you have ever heard of the following genes related to getting breast cancer.

3.2 Have you ever heard of the BRCA1 gene?

1. Yes
2. No
7. **Refuse**
8. **Don't know**

3.3 Have you heard of the BRCA2 gene?

1. Yes
2. No
7. **Refuse**
8. **Don't know**

Women who have a BRCA1 or BRCA2 gene that has been changed, or mutated, have a much higher chance of getting breast cancer.

3.4 In your opinion, what is your chance that you might have a mutated BRCA1 or BRCA2 gene?

1. Very unlikely
2. Unlikely
3. Moderate chance
4. Likely
5. Very likely
7. **Refuse**
8. **Don't know**

3.5 There are some new blood tests that may be able to tell if you have a mutated BRCA1 or BRCA2 gene, which if found would mean that you are likely to be at greater risk of getting breast cancer. If these tests were free, how interested would you be in having them done?

1. Not at all interested
2. Slightly interested
3. Somewhat interested
4. Interested
5. Very interested
7. **Refuse** 8. **Don't know**

[IF ANOT AT ALL INTERESTED, SKIP TO Q3.7.]

3.6 How much money would you be willing to pay out of your own pocket to have this test done?

[RECORD VERBATIM]: \$ _____

3.7 What would be your main reason for having this test?

[RECORD VERBATIM]: _____

Risk Perceptions

The next two questions relate to your thoughts about your risk of getting breast cancer, compared to different groups of women who are your age and African-American.

4.1 Compared to other African-American women your age who do not have a family history of breast cancer, what do you think is your chance of getting breast cancer in your lifetime?

Would you say ... [Read choices 1-5 only.]

1. Much lower
2. Somewhat lower
3. About the same
4. Somewhat higher
5. Much higher

7. **Refuse** 8. **Don't know**

4.2 Compared to other African-American women your age who do have a family history of breast cancer, what do you think is your chance of getting breast cancer in your lifetime?

Would you say ... [Read choices 1-5 only.]

1. Much lower
2. Somewhat lower
3. About the same
4. Somewhat higher
5. Much higher

7. **Refuse**
8. **Don't know**

For the next question, I'd like you to think of your own risk of getting breast cancer, **without** comparing yourself to other women.

4.3 What do you think is your chance of getting breast cancer in your lifetime?

Would you say ... [Read choices 1-5 only.]

1. Very unlikely
2. Unlikely
3. Moderate chance
4. Likely
5. Very likely

7. **Refused** 8. **Don't know**

4.4 How concerned are you about getting breast cancer?
Would you say ...[Read choices 1-5 only.]

1. Not at all concerned
2. Slightly concerned
3. Somewhat concerned
4. Concerned
5. Very concerned
7. **Refuse**
8. **Don't know**

4.5 Please tell me which of the following statements you agree with **MOST**:

1. You have no control at all over whether you get breast cancer.
2. You have a little bit of control over whether you get breast cancer.
3. You have a moderate amount of control over whether you get breast cancer.
4. You have a lot of control over whether you get breast cancer.
5. You have complete control over whether you get breast cancer.
7. **Refuse**
8. **Don't know**

FAMILY HISTORY

5.1 Next I'd like to ask you about family history of breast cancer. Has your mother or any of your sisters or daughters ever been diagnosed with breast cancer?

1. Yes
2. No
7. **Refuse**
8. **Don't know**

[If YES, continue with the next questions; otherwise skip to Q6.1]:

5.2 How did the fact that your relative was diagnosed with breast cancer affect your opinion about your own chances of getting breast cancer? Would you say ...

1. It made you feel that your chances were lower
2. It didn't change your feelings about your chances
3. It made you feel that your chances were a little bit higher
4. It made you feel that your chances were much higher
7. **Refuse**
8. **Don't know**

5.3 The next few questions are to get your impression of how you feel your relative with breast cancer is coping with the disease. Overall, how would you describe her physical health right now?

1. Poor
2. Fair
3. Good
4. Excellent
7. **Refuse**
8. **Don't know**

5.4 Have you seen or talked to your relative with breast cancer in the last month?

1. Yes
2. No
7. **Refuse**
8. **Don't know**

[IF YES, GO TO NEXT QUESTIONS; OTHERWISE, GO TO Q6.1]:

The next items describe how women who have (or have had) breast cancer may feel. Based on your opinion, please tell me how often your family member who has had breast cancer has felt these emotions within the last month.

5.5 In the last month, how much has she been feeling fearful?

1. Not at all
2. A little bit
3. Somewhat
4. Quite a bit
5. A great deal
7. **Refuse**
8. **Don't know**

5.6 In the last month, how much has she been worrying or stewing about things?

1. Not at all
2. A little bit
3. Somewhat
4. Quite a bit
5. A great deal
7. **Refuse**
8. **Don't know**

5.7 In the last month, how much has she been feeling nervous or shaky inside?

1. Not at all
2. A little bit
3. Somewhat
4. Quite a bit
5. A great deal
7. **Refuse**
8. **Don't know**

5.8 In the last month, how much has she been feeling tense or keyed up?

1. Not at all
2. A little bit
3. Somewhat
4. Quite a bit
5. A great deal
7. **Refuse**
8. **Don't know**

5.9 In the last month, how much has she been emotionally upset?

1. Not at all
2. A little bit
3. Somewhat
4. Quite a bit
5. A great deal
7. **Refuse**
8. **Don't know**

5.10 In the last month, how much has she been feeling blue?

1. Not at all
2. A little bit
3. Somewhat
4. Quite a bit
5. A great deal
7. **Refuse**
8. **Don't know**

5.11 In the last month, how much has she been feeling depressed?

1. Not at all
2. A little bit
3. Somewhat
4. Quite a bit
5. A great deal
7. **Refuse**
8. **Don't know**

5.12 In the last month, how much has she been feeling lonely?

1. Not at all
2. A little bit
3. Somewhat
4. Quite a bit
5. A great deal
7. **Refuse**
8. **Don't know**

5.13 In the last month, how much has she been feeling no interest in things?

1. Not at all
2. A little bit
3. Somewhat
4. Quite a bit
5. A great deal
7. **Refuse**
8. **Don't know**

5.14 In the last month, how much has she been feeling hopeless about the future?

1. Not at all
2. A little bit
3. Somewhat
4. Quite a bit
5. A great deal
7. **Refuse**
8. **Don't know**

Psychological Well-being

The following questions are about how **you** have been feeling within the last month. For each question, please give the one answer that comes CLOSEST to the way you have been feeling within the last month. I will repeat the choices if you would like me to.

Within the last month, how much of the time were you ...

6.1 A very nervous person? Would you say ... [Read choices 1-5 only.]

1. None of the time
2. A little bit of the time
3. About half the time
4. Most of the time
5. All of the time
7. **Refused**
8. **Don't know**

Within the last month, how much of the time were you...

6.2 So down in the dumps that nothing could cheer you up?
Would you say ... [Read choices 1-5 only.]

1. None of the time
2. A little bit of the time
3. About half the time
4. Most of the time
5. All of the time
7. **Refused**
8. **Don't know**

Within the last month, how much of the time were you ...

6.3 Calm and peaceful?
Would you say ... [Read choices 1-5 only.]

1. None of the time
2. A little bit of the time
3. About half the time
4. Most of the time
5. All of the time
7. **Refused**
8. **Don't know**

Within the last month, how much of the time were you...

6.4 Downhearted and blue?
Would you say ... [Read choices 1-5 only.]

1. None of the time
2. A little bit of the time
3. About half the time
4. Most of the time
5. All of the time
7. **Refused**
8. **Don't know**

Within the last month, how much of the time were you...

6.5 A happy person?

Would you say ... [Read choices 1-5 only.]

1. None of the time
2. A little bit of the time
3. About half the time
4. Most of the time
5. All of the time
7. **Refused**
8. **Don't know**

Demographics

That's all the questions I have, except I just need to make sure we have your correct address so we can mail your check to you.

7.1a Do you still live at (*read current address*)?

1=Yes

2=No

7=Refuse

8=Don't know

If No , Refused, Don't know = 7.1b

7.1b What is your current address?

Street address/Apt #/PO Box _____
City _____ State _____ Zip _____

Thank you very much for your time and help with our project. The information that you've given us is very valuable, and hopefully will help women in the future to make informed decisions about their own health care. If you have any questions about the project, please call Jenny Terrenoire or Dr. Lipkus at 956-5644. Thank you again for your time.

8.1 Comments:

Total Interview Time: _____.____ minutes

Appendix E

Algorithm used to Stage Women into Mammography Stages of Change

Precontemplation:

- I. Never had a mammogram and is not thinking or planning to have one.

Contemplation:

- I. Never had a mammogram but is thinking or planning to have one.
- II. Had previous one or two mammograms but is now off schedule, and is thinking or planning to get one.

Preparation:

- I. Never had a mammogram but has made an appointment to get one.
- II. Never had a mammogram, is thinking or planning to get a mammogram, and has made an appointment.
- III. Is on schedule for most recent mammogram, without or without thinking or planning to get a mammogram, but has made an appointment to get one.
- IV. Has a previous mammogram, but is now off-schedule, and has made an appointment to get one.
- V. Has had two mammograms on schedule, is or is not thinking or planning to get another mammogram, but has made an appointment to get one.

Action:

- I. Is on schedule for having a mammogram and is thinking or planning to get one. Could have had a previous mammogram to most recent that is off-schedule.

Maintenance:

- I. Has two most recent mammograms on schedule and is thinking or planning to get one.

Relapse risk:

- I. Most recent mammogram is on schedule, but is not thinking or planning to get another mammogram.
- II. Most recent two mammogram are on schedule, but is not thinking or planning to get another mammogram.

Relapsed:

- 1. Had a mammogram but is not thinking or planning to get another and has not scheduled an appointment.
- 2. Most recent mammogram is off schedule but is not thinking or planning to get another and has not scheduled an appointment.

Appendix F

Poster Presentations and Published Reports

**MAMMOGRAPHY SCREENING AND PERCEIVED RISK OF
BREAST CANCER AMONG AFRICAN-AMERICAN WOMEN
WITH A FAMILY HISTORY OF BREAST CANCER**

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Research efforts concerning knowledge about breast cancer screening practices and beliefs of women with a family history of the disease have focused primarily on white rather than African-American women. Compared to white women, African-American women are at higher risk of dying from breast cancer. While it is unclear why African-American women exhibit greater mortality from breast cancer, evidence suggests that these women: 1) underutilize mammography screening, 2) underestimate their risk of breast cancer, and 3) are unfamiliar with the risk factors for breast cancer. This report is based on a baseline telephone interview conducted with 134 African-American women who have a family history of breast cancer, exploring these issues: mammography use, perceived risk of and concerns about breast cancer, and knowledge of breast cancer risk factors.

African-American women with breast cancer were identified via the Duke University Medical Center's tumor registry. Upon gaining permission from the index patient, relatives were contacted by phone, and completed a 15 minute baseline telephone interview. Participants were asked if they had ever had a mammogram, and if so, when they had their most recent mammogram. They were asked how concerned they were about getting breast cancer [not at all (1)/ very concerned], their own perceived lifetime risk of getting breast cancer [very unlikely (1)/very likely (5)], and their lifetime risk compared to other women their age and race [much lower (1)/much higher (5)]. Participants also were

**Keywords: African-American, Mammography
Screening, Risk, Family History**

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asked if they thought any of the following variables were related to getting breast cancer: being older, having a family history of breast cancer, having lots of stress, having a breast injury, having the first child at age 30 or older, never having children, late age of menopause, early age of menarche, and never having breastfed. Response options were yes or no.

Overall, 81% (n = 108) had ever had a mammogram. However, only 55% (n= 31/56) of women ages 50 and older had a mammogram on schedule – defined as having a mammogram every year; 69% (n = 31/45) of women ages 40-49 had a mammogram on schedule – defined as every 1-2 years. These women felt they had a moderate to likely chance of getting breast cancer in their lifetime ($M=3.2$), rated their comparative risk to be the same to somewhat higher than women their age and race ($M=3.4$), and were at least somewhat concerned about getting breast cancer ($M= 3.4$). Own perceived risk correlated positively with comparative risk ($r=.40$, $p<.001$) and concerns about getting breast cancer ($r=.22$, $p<.02$), although they were unrelated to screening history.

Consistent with other findings, these women were unfamiliar with the epidemiological evidence concerning risk factors for breast cancer. On a composite score ranging from 0 – 9, the mean correct response was 3. Of import, only 44% (n = 59) knew that increasing age was a risk factor for breast cancer, although 90% (n= 120) correctly identified family history as a risk factor – the two major risk factors for breast cancer. In addition, 59% and 45% erroneously believed that having a breast injury or experiencing high levels of stress were related to getting breast cancer, respectively. Greater risk factor knowledge related, albeit weakly, with enhanced own and comparative risk ($r=.26$ and $.19$, respectively, $p<.03$), and concerns with getting breast cancer ($r=.23$, $p<.01$).

These preliminary results suggest that the majority of these African-American women with a family history of breast cancer have had a mammogram, although younger rather than older women are having mammograms on schedule. Furthermore, unlike previous findings in the literature, these women do acknowledge their greater risk of getting breast cancer due to a family history. Overall knowledge of risk factors for breast cancer was poor, and at least half failed to realize increasing age as a strong correlate of breast cancer. Based on these preliminary results, greater efforts should be directed at increasing mammography screening among older African-American women and enhancing knowledge of breast cancer risk factors.

Running Header: RISK PERCEPTIONS AMONG AFRICAN-AMERICAN WOMEN

Relationships among Breast Cancer Concern, Risk Perceptions and Interest in Genetic Testing for Breast
Cancer Susceptibility among African-American Women with and without a Family History of Breast
Cancer

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and

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Abstract

There has been very little research exploring the relationships among perceptions of and concern about getting breast cancer, and interest in genetic testing for breast cancer among African-American women with and without a family history of breast cancer. This study explored these issues among 130 and 136 African-American women with and without a family history of breast cancer, respectively. Women with a family history reported having greater perceived breast cancer risks and concerns than women without a family history of breast cancer. Knowledge of breast cancer risk factors was very poor, and correlated weakly with perceptions of risk and concern. In attributional analyses, acknowledging one's family history status was the strongest predictor of perceived risk only among women with a family history. Women with a family history of breast cancer expressed greater interest in genetic testing for breast cancer susceptibility than women without a family history, although interest in testing was high overall. Increasing perceptions of breast cancer risks and concerns were related to greater interest in genetic testing, and this relationship was not moderated by family history status. Attributions of risk and knowledge of breast cancer risk factors generally were not related to interest in testing. Overall, these results suggest that: 1) African-American women with a family history are more concerned about and do recognize their greater risk of breast cancer, 2) knowledge of risk factors and attributions of risk are not directly related to interest in genetic testing, and 3) concerns, rather than beliefs about one's risk, are more powerfully related to interest in genetic testing, independent of family history status.

Relationships Among Breast Cancer Concerns, Risk Perceptions and Interest in Genetic Testing for Breast Cancer Susceptibility among African-American Women with and without a Family History of Breast Cancer

Since the discovery of BRCA1 and BRCA2, increased research attention has been devoted to factors that promote interest in, and reactions towards, genetic testing for breast cancer susceptibility. Most of our knowledge in these areas is derived from Caucasian women rather than other racial groups, such as African-Americans. What little is known suggests that African-Americans, despite having more positive attitudes about the benefits of genetic testing than Caucasians, are less interested in genetic testing for breast cancer, and are less likely to attend educational or counseling sessions about BRCA1 (1-4). Unfortunately, these studies have not examined interest in genetic testing for breast cancer susceptibility comparing African-American women with and without a family history of breast cancer. By assessing correlates of and interest in genetic testing among African-American women with and without a family history of breast cancer, community and clinical interventions can provide targeted educational programs addressing the specific needs of women at different risk. Such programs would address issues and misperceptions most pertinent to African-American women at different risks about the appropriateness of genetic testing to help them make informed decisions.

This paper has three goals. First, we assess whether family history status among African-American women differentially predicts interest in genetic testing for breast cancer susceptibility. Second, we assess whether interest in genetic testing is related to two factors correlated with desire for testing, perceptions of breast cancer risk and concerns (5-8), and whether family history status moderates these relationships. In so doing, we examine whether these two groups differ in their perceived breast cancer risks and concerns. Third, we assess whether attributions of risk and knowledge of breast cancer

risk factors are related to perceived risk and interest in genetic testing. Studies show that knowledge of personal risk factors may not predict interest in testing independently of overall perceived risk and worry (6,9). Thus, while attributions and knowledge may be related to breast cancer risks, they also may relate directly to interest in testing.

We first provide a brief theoretical review as to why breast cancer risk and concerns should be related to interest in genetic testing for breast cancer susceptibility. We then review African-Americans' perceptions of their breast cancer risks and worries, and state the study predictions.

Theory linking breast cancer risk perceptions, concerns, and interest in genetic testing

This study examines two processes that can affect intentions to be tested for breast cancer susceptibility: cognitions (i.e., perceived risk) and affect (i.e., breast cancer concerns). Models of health behavior, such as the Health Belief Model, Protection Motivation Theory, and the Precaution Adoption Model, suggest that increased perceived risk should facilitate behavior change (10-14), and that emotions (e.g., fear, anxiety, worry) may serve a similar purpose (15-18). Moreover, high levels of perceived risk may lead to modest increases in breast cancer worries and distress (19). Based on the Parallel Response Model and the Extended Parallel Process Model (20-21), when people experience high threat (i.e., high risk + severity) and negative affect (e.g., fear), they may engage in two processes: danger control and fear control. Danger control is aimed at removing or reducing the source of threat; fear control is aimed at removing or reducing the negative emotions produced by the threat.

Genetic testing can accommodate both these processes. Knowing that one is not a carrier of a BRCA1 or BRCA2 mutation should reduce heightened perceived breast cancer risk and negative affect (e.g., anxiety; 22). Learning that one is a mutation carrier may lead to actions to increase a person's control over the danger of getting breast cancer. For example, carriers may choose to undergo

prophylactic mastectomy to reduce risk. Indeed, Lerman and colleagues (6, 23) found that even the expectation of testing positive for a BRCA1 mutation was related to feelings of greater control. In sum, greater perceived breast cancer risks and concerns can promote interest in genetic testing since: 1) a negative test result should reduce perceived risk and one's negative affect surrounding perceived risk, and 2) a positive test result can lead to decisions and medical procedures that enhance one's sense of control over reducing the risk.

Perceptions of breast cancer risk among African-American women

African-American women typically view themselves to be at low risk of cancer generally, and breast cancer specifically (24-30; see 19, 31 for exceptions). This is even true for those with a family history (32-33) perhaps because they fail to recognize family history as a predictor of risk (31). This interpretation is consistent with African-Americans' generally poor knowledge of breast cancer risk factors (30, 34), and suggests that: 1) educating these women about breast cancer risk factors is needed, and 2) erroneous knowledge of breast cancer risk factors and causes (i.e., attribution) may ultimately affect interest in genetic testing directly or by affecting perceptions of risk.

Of import, if perceived risk is linked to interest in genetic testing, then it is worthwhile to: 1) understand correlates that increase or decrease perceived risk, such as knowledge of breast cancer risk factors and attributions of risk (i.e., reasons why women report a specific level of risk, 35-37), and 2) whether these correlates are related to interest in testing. This information would address whether interventions pertaining to interest in genetic testing need to target overall perceived risk and/or specific underlying correlates of risk that promote interest in testing differently among African-American women at different risk. This study begins to explore these issues.

Perception of breast cancer concerns

Studies of African-American women's worries about getting breast cancer show inconsistent findings. Some studies show that older African-American women express low levels of breast cancer worry (38), while other studies, including those with a family history of breast cancer, show elevated levels of worry (31, 33). Moreover, African-Americans appear to be more concerned about breast cancer compared to Caucasian women (33, 39).

Study hypotheses:

Using a sample of African-American women with and without a family history of breast cancer, the present paper tested the following predictions:

H1: Women with a family history of breast cancer will report greater perceived breast cancer risks and concerns than women without a family history of breast cancer.

H2: Women will most often mention heredity and personal action causes (e.g., diet, exercise, get mammograms) as determinants of their perceived lifetime breast cancer risk.

H3: Women with a family history of breast cancer will report greater interest in genetic testing for breast cancer than women without a family history of breast cancer.

H4. Perceptions of breast cancer risk and concern will be related to greater interest in genetic testing for breast cancer susceptibility. However, family history status will interact with (i.e., moderate) these relationships. Specifically, breast cancer risks and concerns will be related more powerfully to interest in genetic testing among women with, rather than without, a family history.

H5. Knowledge that family history is related to breast cancer risk will be related to interest in genetic testing. Similarly, attribution of risk to heredity will be related to interest in genetic testing.

Methods

Participants:

Women with a family history were recruited by first contacting a first-degree relative (N=91) diagnosed with breast cancer based on the information provided by Duke University Medical Center's Tumor Registry. Data on stage, length since and mean age at diagnosis were available on 69 out of the 81 breast cancer patients who consented to give the names of their relative(s) – this information can be obtained from the first author upon request. Referring patients at times provided the names and phones numbers of more than one first-degree relative.

The sample of African-American women without a family history of breast cancer (i.e., controls) was obtained from a sampling frame of all African-American women who attended the Duke Radiology Department within the last 3 1/2 years. To obtain comparability between groups, controls were matched with women with a family history based first on age (within \pm 6 months), and then on mammography history (\pm 3 months of most recent mammogram). Since this study was aimed primarily at affecting mammography screening, age and most recent mammogram were viewed as the two most critical matching variables based on the limited sample size of African-American women. Including other matching variables, such as education, would have resulted in fewer successful complete matches.

Attempts were made by phone to recruit 384 women (233 controls and 151 with a family history). Of these 384 attempts, 194 controls and 151 women with a family history were reached. Among those reached, 45 controls and 15 women with a family history refused to participate, and one control and two women with a family history initially consented to participate and later revoked consent at the time of the baseline interview. In addition, 12 controls and four women with a family history could not participate for other reasons (e.g., health reasons, wrong race). The final sample consisted of

130 (86% response rate) and 136 (70% response rate) African-American women with and without a family history of breast cancer, respectively. The demographic characteristics of study participants are presented in Table 1. The groups did not differ significantly on any of the demographic characteristics. Overall, 111 successful matches were made on age, including 75 matches on both age and screening history. Only 15 women with a family history of breast cancer could not be matched with a control.

Insert Table 1 about here

Procedure

Data presented here are based on all participants who completed a baseline telephone interview and agreed to be part of a larger mammography intervention study -- results will be presented in forthcoming articles. Study participants were mailed a cover letter stating that the purpose of the study was to educate African-American women about breast cancer risk factors and mammography. Within two weeks of the mail-out, a trained telephone interviewer from the Duke Risk Communication Laboratory contacted potential participants, reminded them of the purpose of the study, and completed a fifteen-minute baseline interview. The interview consisted of obtaining information on the following variables relevant to this paper:

Demographics: Age, education (ranged from less than high school to graduate work), marital status (married, living as married, single, divorced, widowed, and separated), and work status (full/part-time, unemployed, full-time homemaker, retired).

Perceptions of risk: Perceived lifetime risk was assessed, using a five-point Likert scale, by asking "What do you think is your chance of getting breast cancer in your lifetime?" Response options were: very unlikely, unlikely, moderate chance, likely, and very likely.

Attributions of risk: After responding to their perceived lifetime risk, women were asked: "In the previous question, you mentioned that your risk of getting breast cancer was (repeat response woman gave). What things did you think about that led you to choose that answer?" Responses were subsequently coded by two coders (99% agreement) into one of the categories used by Aiken et al. (35) based on Weinstein's (37) scheme: personal actions (e.g., exercise, diet, do not smoke, get mammograms), heredity (e.g., family history), physiological causes (e.g., lumps in breast(s), no children, age), environment (e.g., pesticides), psychological (e.g., personality, being optimistic), and chance (e.g., luck).

Knowledge of breast cancer risk factors: Women were asked (yes/no) whether nine variables were related to getting breast cancer. Variables were selected from the epidemiological literature and other knowledge questionnaires (34, 40-42) and included: 1) being older, 2) having a family history, 3) having lots of stress, 4) having a breast injury (e.g., bruise), 5) being older (e.g., >30) when you have the first child, 6) never having children, 7) late age of menopause (>55), 8) early menarche (< 12), and 9) never having breastfed. Alpha for the knowledge scale was .59.

Breast cancer concerns: Participants were asked on a five-point likert scale, "How concerned are you about getting breast cancer?" Response options were: not at all concerned, slightly concerned, somewhat concerned, concerned, and very concerned.

Interest in genetic testing for breast cancer: was assessed using the following question: "There are some new blood tests that may be able to tell you if you have a greater chance of getting breast cancer because of something that might have been passed down to you from your blood relatives, that is, through your genes. If this test was free, how interested would you be in having it done?" Response options were: not all interested, slightly interested, somewhat interested, interested, and very interested.

Results

Overview: We first discuss whether there were differences in breast cancer risk perceptions and concerns, attributions of risk, and knowledge of breast cancer risk factors between women with and without a family history of breast cancer. The purpose of these analyses was to establish group differences that may subsequently relate to interest in genetic testing, which formed the basis for the second set of analyses.

Perceptions of breast cancer risk and worry as a function of family history status

It was expected that women with a family history of breast cancer would report greater perceived breast cancer risk and concerns than women without a family history. As predicted, bivariate relationships revealed that women with a family history perceived themselves at greater risk ($X_{(1)}^2 = 31.2$, $p < .0001$ for trend), and were more concerned about getting breast cancer than women without a family history ($X_{(1)}^2 = 7.4$, $p < .007$ for trend). Whereas 24%, 52% and 14% of women without a family history reported below-average, average or above-average risk, respectively, 14%, 40% and 46% of women with a family history reported below-average, average or above-average risk, respectively. Similarly, whereas 40%, 27% and 33% of women without a family history reported being not at all/slightly concerned, somewhat concerned, and concerned/very concerned about getting breast cancer, respectively, 31%, 21% and 48% of women with a family history reported not at all/slightly concerned, somewhat concerned, and concerned/very concerned about getting breast cancer, respectively. Based on the contingency table phi statistic, risks and concerns were positively correlated among women with and without a family history (phi = .59 and .53, $p < .001$, respectively). Mammography screening did not affect perceived risk or concern.

Attributions of risk

Having established that perceptions of risk differed among these two groups of women, we sought to further understand the underlying correlates of women's perceptions of risk by analyzing their attributions of risk. These relationships were analyzed via three different strategies. First, we examined the pattern of relationships between attributional domains and women's ratings of their risk, controlling for family history status. Second, we examined whether women with and without a family history differed in the frequency with which they mentioned a specific category. Third, we examined whether family history status interacted with attributional domains to predict perceptions of risk. Since environmental, psychological and chance causes were mentioned by less than 1% of the participants, these domains will not be discussed further.

There were no significant overall bivariate relationships between risk perceptions and heredity and physiological causes. However, women who reported personal action causes were significantly more likely to report less risk than women who did not mention personal action causes ($\chi^2_{(1)} = 20.1$, $p < .001$ for trend). Taking into account family history status, women with rather than without a family history of breast cancer were more likely to mention heredity causes (66.9% vs. 47.7%, $\chi^2_{(1)} = 9.9$, $p < .002$), and less likely to mention physiological (22.3% vs. 34.8%, $\chi^2_{(1)} = 4.9$, $p < .03$) and personal action causes (16.9% vs. 52.2%, $\chi^2_{(1)} = 36.4$, $p < .001$). The pseudo-homogeneity statistic (43), which tests whether the homogeneity of effect sizes between attributions of risk and perceived risk differ by strata, revealed that the relationship between perceived risk and heredity differed by family history status ($\chi^2_{(1)} = 17.5$, $p < .001$). Women with a family history who mentioned heredity causes (e.g., having a family history of breast cancer) were more likely to report greater risk ($\chi^2_{(1)} = 17.5$, $p < .001$). Among women

without a family history, there was no relationship between the mentioning of heredity causes (e.g., not having a family history) and perceived risk ($\chi^2_{(1)} = 2.6$, $p > .10$).

Knowledge of breast cancer risk factors as a function of family history status

It was predicted that knowledge of breast cancer risk factors would be low. Degree of knowledge was scored as follows: a correct response to each of the nine potential risk factors received a score of 1; incorrect or "don't know" responses received a score of 0. The percentage of correct responses to each of the nine knowledge items by family history status is presented in Table 2.

Insert Table 2 about here

Inspection of Table 2 reveals that women with and without a family history had poor knowledge of breast cancer risk factors. Less than 45% of women in both groups correctly knew that growing older, having no children or having the first child after age 30, late age of menopause, early menarche, and never having breastfed were related to an increased breast cancer risk. Furthermore, only 42% knew that stress was not related to breast cancer risk, and 28-34% knew that injury to the breast(s) did not increase breast cancer risk. However, a high proportion of women in both groups ($> 88\%$) correctly mentioned family history as a risk factor. Subsequent chi-square tests revealed no significant differences in proportions of correct responses to each knowledge item between women with and without a family history of breast cancer. Creating a total knowledge score by summing across items revealed that both groups of women correctly identified a median of three items.

Relationships between individual knowledge items and perceived risk revealed only one significant finding after controlling for the number of tests performed (.05/9, alpha = .005). Women who correctly responded that having a child after age 30 increases risk were more likely to perceive themselves at higher risk ($\chi^2_{(1)} = 10.9$, $p < .001$ for trend). Relationships between each knowledge item

and risk did not differ by family history status. Spearman correlations were conducted to assess relationships between the total knowledge score and perceived breast cancer risk and concern by group. Among women with a family history, those who had more knowledge reported greater risk ($r = .19$, $p < .04$) and felt more concerned about getting breast cancer ($r = .22$, $p < .02$). Among women without a family history, knowledge was unrelated to perceived risk and concern ($p = .12$ and $.13$, respectively).

Relationships between interest in genetic testing and family history status.

It was predicted that women with a family history of breast cancer would report more interest in being tested for breast cancer susceptibility than women without a family history. As predicted, there was a significant linear bivariate relationship between interest in genetic testing and family history status ($\chi^2(1) = 6.3$, $p < .02$ for trend). Among women with a family history, 11%, 17% and 72% reported being not at all/slightly interested, somewhat interested, and interested/very interested, respectively. Among women without a family history, 25%, 16% and 58% reported being not at all/slightly interested, somewhat interested, and interested/very interested, respectively.

Relationship between interest in genetic testing and perceived breast cancer risks and concerns.

It was predicted that women who perceived greater risk and were more concerned about breast cancer would report greater interest in genetic testing. This prediction was confirmed for both perceived risk ($\chi^2(1) = 4.4$, $p < .04$ for trend) and concern ($\chi^2(1) = 13.3$, $p < .001$ for trend). The 5 x 5 contingency tables can be obtained from the first author upon request.

Relationship between interest in genetic testing and knowledge of breast cancer risk factors

It was expected that knowledge of family history as a risk factor would be related to interest in genetic testing for breast cancer susceptibility. No other a-priori predictions were made. Bivariate relationships were computed between each of the nine knowledge items and interest in genetic testing

stratifying by family history status. Due to the number of tests conducted, we used a more conservative type I error of .005. As predicted, there was an overall significant trend between acknowledging family history status as a risk factor and interest in genetic testing ($\chi^2_{(1)} = 12.7$, $p < .0001$). Specifically, among both groups, women who knew that family history was related to increased breast cancer risk expressed a stronger desire to get tested than women who did not ($p < .02$ for trend within groups). Among women without a family history who correctly attributed family history with greater risk, 61% were more than somewhat interested in genetic testing, compared to 33% who were not aware of this association. Among women with a family history, 74% versus 53% were more than somewhat interested. No other significant effects were found.

Relationship between interest in genetic testing and attributions of risk

It was expected that interest in genetic testing would be most strongly associated with heredity explanations. Bivariate analyses, stratified by group, revealed no significant trends between interest in genetic testing and any attributional domain overall or within groups. There were no indications that family history status interacted with attributional domains to affect interest in genetic testing.

Mutivariate analyses relating interest in genetic testing for breast cancer susceptibility and breast cancer perceived risk and concern

It was predicted that risk and concern would be related more powerfully to interest in genetic testing among women with rather than without a family history. To test these predictions, we conducted hierarchical proportional logistic regression models. Step one included age, education, marital, and family history status; step two included the main effects of risk or concern, and step three included risk/concern by family history status interactions. In these analyses, having a high school education or less, being married or living as married, not having a family history of breast cancer, perceiving oneself

as being very unlikely to get breast cancer, and being not at all concerned about getting breast cancer served as reference groups (coded 0). We assessed the fit of each model by testing the chi-square difference between each successive step (e.g., chi-square difference between main effects and interaction models).

The initial models revealed a violation of the proportional odds assumption regressing interest in genetic testing onto the risk main effect and interaction model. The assumption continued to be violated when interest in genetic testing was collapsed into three tiers: 1) not at all and slightly interested, 2) somewhat interested, and 3) interested and very interested. Consequently, interest in testing was collapsed into two categories for all analyses: being somewhat, slightly or not at all interested versus being interested and very interested.

Overall, there were no significant risk main effects or risk by family status interactions. Interest in genetic testing was related to being concerned about getting breast cancer as a main effect, but not as an interaction. The final logistic regression model including concern is reported in Table 3. Women who reported being very concerned were significantly more likely to report being interested or very interested in genetic testing for breast cancer susceptibility than women who reported being not at all concerned. In addition, women who were not married expressed less interest in genetic testing than those who were married.

Insert Table 3 about here

We also examined whether the single significant bivariate relationship between knowledge of family history status as a risk factor continued to predict interest in genetic testing using the same multivariate modeling procedures. There was no significant main effect for knowledge of family history

as a risk factor, or an interaction with family history status. Since none of the attributional domains were significantly related to interest in genetic testing, multivariate modeling was not performed.

Discussion

The major aim of this study was to assess differential interest in breast cancer genetic testing among African-American women with and without a family history of breast cancer, and correlates of interest. Overall, 72% of our sample of African-American women with a family history expressed being interested or very interested in genetic testing compared to 58% of the women without a family history. These rates among women with a family history are comparable, though lower, than other studies using primarily caucasian first-degree relatives of women with a family history of breast or breast and ovarian cancer. Among those studies, interest in genetic testing for breast cancer susceptibility has ranged from 75%-95% (6, 7, 23). We are unaware of any study to compare directly our results to a comparable sample of African-American women with a family history. Similarly, only indirect comparisons can be made between our results pertaining to women without a family history and those of two other studies. In a statewide telephone survey in Kentucky, Andrykowski and colleagues (2) found that among non-caucasian women, of which African-Americans constituted the largest subpopulation, 76% expressed interest in being told of their personal genetic breast cancer predisposition. Based on women enrolled in an HMO, Tambor and colleagues (1) found that among those not interested in genetic testing, 20% were African-American. Thus, comparing our findings to these two studies, and assuming that in the latter two studies African-American women had no family history, our sample expressed less interest in testing.

Women without a family history expressed significantly greater interest in testing than women without a family history, in the bivariate analysis only. We examined whether breast cancer risk

perceptions and concerns could partly explain differences in interest in testing among these two groups. Specifically, it was expected that differences in interest would be reflected by different levels of perceived breast cancer risk and concern such that these two mechanisms would predict more powerfully interest among women with rather than without a family history of breast cancer. Whereas perceived risk and concern were related to interest in testing in bivariate analyses, there were no significant interactions between these constructs and family history status.

Given that perceived lifetime risk was related to interest in testing, we addressed two relevant issues: 1) the underlying correlates of risk, specifically knowledge of breast cancer risk factors and attributions of risk, and 2) the extent to which knowledge of breast cancer risk factors and attributions of risk correlated with interest in genetic testing. With respect to correlates of risk, attributions to heredity causes were related more strongly to increased perceived risk among women with a family history. Among women without a family history, attributions to heredity were unrelated to perceived risk. Knowledge of breast cancer risk factors was a very weak correlate of risk and concern. With respect to interest in genetic testing, correctly acknowledging family history status as a risk factor was related in bivariate, but not multivariate analyses. None of the attributional domains were related to interest in testing.

What are the implications of these findings for pre-test genetic counseling and decision-making among African-American women at different risk? We offer three suggestions. First, while perceptions of risk and concern both were related to interest in genetic testing, being concerned about getting breast cancer was related more strongly to testing. Indeed, in an exploratory logistic regression analysis controlling for family history status, when the main effects of perceived lifetime risk were added to a model with the main effects of being concerned, only being very concerned was related to greater

interest in genetic testing compared to women not at all concerned. Therefore, genetic counselors should focus on the emotional precursors and aftermath of testing such as women's concerns about getting breast cancer (44).

Second, genetic counselors and other health educators should emphasize how risk is related to family history status, which may then affect desire to test. Counseling and educational programs emphasizing family history may more powerfully dissuade women at lower risk from getting testing. Unlike other studies (32), the majority of this sample knew that having a family history increased one's risk for breast cancer, but a significant proportion (i.e., about 10% in both groups) did not identify correctly family history status with being at increased risk. Therefore, there is a need to continue educating African-American women about how family history status, and other risk factors (e.g., age), contribute to breast cancer risk. However, among the two groups of women studied, those without a family history may need the link between family history status and risk reinforced. As the attributional analyses revealed among these women, perceived risk was unrelated to attributions to heredity causes.

Third, attributions may ultimately influence testing through their effects on risk perceptions. In this regard, efforts to help women make informed decisions about testing should focus on personal action causes (e.g., exercise, dietary habits, smoking behavior, getting mammograms, etc.) in relations to perceived risk. Women who mentioned "beneficial" personal action causes (e.g., diet, exercise, getting mammograms) were significantly less likely to report increased risk than women who did not mention personal action causes. What is relevant for counseling is that women who feel they engage in detrimental behaviors, may also feel themselves to be at higher risk, which may then be related to greater interest in testing. Therefore, counseling may affect interest in testing by targeting lifestyle factors that women feel may put them at higher risk. Lifestyle factors may be the most salient reasons why women

without a family history desire testing for breast cancer susceptibility. Indeed, women without a family history mentioned significantly more personal action causes to explain their perceptions of risk than women with a family history.

Our findings need to be interpreted in light of several methodological issues. First, we used as controls women who attended a radiology clinic. It is unclear to what extent the results might have differed if controls had been obtained through a random community sample. Second, we used single measures of the main outcomes, a method which commonly raises questions about item reliability and validity. Single-item measures of perceived breast cancer risk are commonly used in studies with African-American women (e.g., 19, 45), and to date, there is no measure of perceived risk that is clearly superior (46) or consistently used to study risk in African-American populations. Similarly, there is no “gold standard” question(s) to evaluate interest in genetic testing among African-American women. The results pertaining to breast cancer concerns may have differed should we have used more in-depth measures such as Lerman and colleagues (47) worry scale, or the three-item worry scale used by McCaul and colleagues (48). However, given that the baseline interview had to assess several constructs, to reduce respondent burden, we felt that face valid single-items would suffice. Nonetheless, future research should use more comprehensive measures of the constructs explored in this study. Third, we did not collect additional data pertaining to knowledge about BRCA1 or BRCA2 testing (e.g., have they ever heard of these genes), and reasons for getting tested; data are being collected on these issues. Preliminary results suggest that for both groups, the main reason to test is to find out whether they are at higher risk (approximately 50% mentioned this reason). Neither did we assess how many of these women, if offered testing, would accept and attend. Fourth, we assessed only one emotional reaction to getting breast cancer (i.e., concerns); other emotional responses, such as fear and anxiety, should be

assessed. Finally, while we assessed attributions for risk, we did not ask women why they felt concerned about getting breast cancer. We suspect that our population would have had a difficult time separating attributions for risk and concern, thereby resulting in highly similar responses. Future research should address specifically the underlying causes of concern related to breast cancer risk.

Lastly, readers are cautioned to interpret these findings in terms of women's hypothetical interest in genetic testing. A more "realistic" portrayal of interest in testing would have been achieved if these women were given information concerning the complexities involved in genetic testing. For example, we did not provide information about the risks and benefits related to genetic testing. We did not mention the likelihood of breast cancer occurrence among women who do test positive. Being informed of the high likelihood of occurrence may dissuade some women from testing. Nor did we discuss some of the potential ramifications of testing positive for issues related to family decisions (e.g., having children), potential negative emotional side-effects of testing, possible treatment options, and issues related to confidentiality and health insurance. The failure to discuss these issues likely desensitized women to the complexities involved in genetic testing, some of which may have served to reduce interest in testing. Future studies exploring interest in genetic testing for breast cancer susceptibility among African-American women at different risks should provide information regarding these issues to more powerfully assess how they affect interest in and actual testing. Despite these limitations, this study provides rather detailed information about perceptions of breast cancer risk, and also preliminary data about interest in genetic testing in two rarely compared groups of African-American women.

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Table 1

Demographic Characteristics of Women with and without (Control) a Family History of Breast Cancer

<u>Characteristic</u>	<u>Controls</u>		<u>Family History</u>	
	<u>N</u>	<u>%</u>	<u>N</u>	<u>%</u>
<u>Age</u>				
< 40	25	43.1	33	56.9
40 – 49	52	54.7	43	45.2
50 ≥	59	52.2	54	47.8
High school education or less	48	35.5	42	32.0
Married or living as married	69	51.1	56	43.1
Work full-time	82	60.7	78	60.0
<u>Afflicted family member</u>				
Mother	---	---	72	55.9
Sister	---	---	41	31.5
Daughter	---	---	1	.8
Mother and one sister	---	---	9	6.9
Mother and two sisters	---	---	1	.8
Two sisters	---	---	5	3.8
Three sisters	---	---	1	.8

Table 2

Proportion of Correct Responses to the Breast Cancer Knowledge Items by Family History Status.

<u>Knowledge item</u>	<u>Controls</u>	<u>Family History</u>
Being older	44.8%	43.8%
Having a family history of breast cancer	90.4%	88.5%
Having lots of stress	41.9%	40.8%
Having a breast injury	27.9%	33.9%
Being older when you have your first Child	31.6%	42.3%
Never having had children	20.6%	23.1%
Late age of menopause	39.0%	28.5%
Early age of starting periods	22.1%	18.5%
Never having breastfed	17.0%	21.5%

Note. Percentages represent the proportion of women who correctly identified each variable as a possible risk factor. For having a breast injury or lots of stress, the numbers represent the proportion of women who knew that having a breast injury or lots of stress is not related to an increased risk of breast cancer.

Table 3

Logistic Regression Model Predicting Interest in Genetic Testing for Breast Cancer Susceptibility from the Main Effects of Breast Cancer Concerns.

<u>Variable</u>	<u>Odds Ratio</u>	(95% C.I.)
Age	.55	(0.32, 0.96)
<u>Education</u>		
High school or less	1.00	
Greater than high school	1.21	(0.66, 2.20)
<u>Marital status</u>		
Married or living as married	1.00	
Other	.52*	(0.30, 0.91)
<u>Family history status</u>		
No family history	1.00	
Has a family history	1.68	(0.97, 2.92)
<u>Concerned about breast cancer</u>		
Not at all concerned	1.00	
Slightly concerned	1.00	(0.42, 2.39)
Somewhat concerned	1.82	(0.75, 4.39)
Concerned	2.56	(0.99, 6.64)
Very Concerned	3.09*	(1.19, 8.03)

Note. Model was predicting the probability of being interest or very interested in testing. Age was treated as a continuous variable with the odds ratio and confidence intervals referring to comparisons between women one standard deviation (± 13 years) above and below the mean. * $p < .05$.



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